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# "Everything Remains Uncertain": Theorizing Parents' Communication About Uncertainty, Hope, and Hopelessness While Managing Complex Pediatric Chronic Conditions

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“EVERYTHING REMAINS UNCERTAIN”:  
THEORIZING PARENTS’ COMMUNICATION ABOUT UNCERTAINTY, HOPE,  
AND HOPELESSNESS WHILE MANAGING COMPLEX PEDIATRIC CHRONIC  
CONDITIONS

by

Katherine A. Rafferty

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ABSTRACT  
“EVERYTHING REMAINS UNCERTAIN”: THEORIZING PARENTS’  
COMMUNICATION ABOUT UNCERTAINTY, HOPE, AND HOPELESSNESS  
WHILE MANAGING COMPLEX PEDIATRIC CHRONIC CONDITIONS

by

Katherine A. Rafferty

The University of Wisconsin-Milwaukee, 2015  
Under the Supervision of Dr. C. Erik Timmerman

Navigating a child’s chronic illness and treatment is particularly challenging for parents and parental surrogates. These experiences may add to parents’ feelings of uncertainty. During this time, many parents report the need to be the “bearer of hope” for their child, regardless of the challenges that may prevent this from being possible. Researchers studying hope and uncertainty have acknowledged that these two concepts co-exist during the parental caregiver experience and effected by external factors (e.g., medical information or conversations with other people); however, a dearth of research remains about parents’ meanings and interactions that influence their social constructions of uncertainty, hope, and hopelessness. Therefore, studying parents’ talk about their experiences with uncertainty, hope, and hopelessness as they continue to manage their child’s chronic condition and treatment is one way to glean this important information. Subsequently, a grounded theory analysis was conducted on 35 parent interviews about their experiences with uncertainty, hope, and hopelessness as their chronically ill child received ongoing medical or pharmacological treatment. Across the parents interviewed, *comparing self to others* was the core category that emerged from parents’ talk and connected the categories and subcategories within the model (see Figure 1). *Comparing self to others* was described as a recursive communicative and psychological process that

involved seeking information and assigning meaning to differences. Within parents' comparisons, they communicated that information seeking and holding conversations with others (e.g., other parents, friends, healthcare providers) provided them with a meaningful understanding of their circumstances as they proceeded to construct their "new normal," and also assisted them with navigating the tensions between hope and hopelessness. Thus, an analysis of parents' talk revealed how everyday conversations and interactions (e.g., online information-seeking), as well as larger social meanings, may have an effect on parents' constructions of uncertainty, hope, and hopelessness. This information may be useful for developing messages within family-based interventions and educating medical professionals and other non-profit organizations that interact and serve families with chronically ill children.

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To the parents that I met, thank you for sharing your stories – your commitment and love for your family and children are truly an inspiration!

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And most importantly, to My Heavenly Father, who is always faithful with His abundant blessings without regard to worthiness. I consecrate this dissertation to the greater glory and honor of Your Name.

“For I know well the plans I have in mind for you—oracle of the Lord—plans for your welfare and not for woe, so as to give you a future of hope” (Jeremiah 29:11).

## TABLE OF CONTENTS

Introduction and Theoretical Orientation	1
Significance of Studying Parents' Uncertainty	3
Significance of Studying Parents' Hope and Hopelessness	4
Rationale for the Use of Qualitative Methods	6
Grounded Theory	7
Purpose of Dissertation	10
Research Questions	11
Outline of Dissertation Chapters	11
Review of Literature	13
Family Caregiving during Chronic Illness	13
Family Caregiving during Pediatric Chronic Illness	16
Parents as Primary Caregivers during Pediatric Chronic Illness	18
Significance of Studying Parental Uncertainty, Hope, and Hopelessness	20
Parental Caregivers' Uncertainty	21
Parental Caregivers' Hope	24
Parental Caregivers' Hopelessness	26
The Interpersonal Nature of Uncertainty, Hope, and Hopelessness	27
Advancing Knowledge on the Social Construction of Parents' Uncertainty, Hope, and Hopelessness by Analyzing Parents' Talk	32
Relevant Communication-based Theories	34
Relational Dialectics Theory	35
Uncertainty Management Theory	36
Communicated Narrative Sense-making	37
Rationalization for a Grounded Theory Study	38
Methods	41
Research Sample	42
Primary Research Location	43
Secondary Research Location	45
Data Collection	45
Procedure	46
Initial Screening	48
Semi-structured Interviews	48
Demographic Questionnaire	49
Data Analysis and Synthesis	49
Other Methodological Considerations	55
Researcher Positionality and Reflexivity	55
Establishing Trustworthiness in the Research Process	60
Ethical Considerations and Institutional Review Board Approval	62

Results	64
Summary of the Theoretical Model	64
Parents' Core Social Process: Comparing Self to Others	66
Seeking Information	67
Assigning Meaning to Differences	70
Acknowledging Chronic Uncertainty	73
Feeling Heightened Emotions	75
Waiting Endlessly	78
Questioning the Future	80
Constructing the "New Normal"	84
Making Changes	85
Striving for Normalcy	88
Feeling Hopeless and Maintaining Hope	92
Experiencing Overwhelming Obstacles	93
Dreading the What-ifs	98
Suffering from Anticipatory Grief	100
Finding a Supportive Community	104
Relying on Religious and Spiritual Beliefs	110
Reframing Towards Positivity	113
Summary and Preview of Next Chapter	119
Discussion	121
Major Conclusions	122
The "New Normal" Metaphor Described as a Response to Living in Chronic Uncertainty	122
The Social Construction of Parents' Uncertainty, Hope, and Hopelessness was a Product and Process of Social Meanings and Everyday Talk	124
<i>Comparing Self to Others</i> Assisted Parents with Navigating the Tensions Between <i>Maintaining Hope</i> and <i>Feeling hopeless</i>	128
Positive Communication and Support Facilitated Parents' Construction and Maintenance of Hope	132
Theoretical Implications	138
Practical Implications	142
Limitations	145
Directions for Future Research	147
Conclusion	149
References	151
Appendices	194
Semi-structured Interview Guide	194
Questionnaire	196
Recruitment Flyer	199
Curriculum Vitae	200

## LIST OF FIGURE

Figure 1: Grounded Theory of Parents' Talk about Uncertainty, Hope, and Hopelessness	191
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## LIST OF TABLES

Table 1: Family Demographics of Participants	192
Table 2: Emerging Theory: Theoretical Category, Category, Themes	193

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## **Chapter 1: Introduction and Theoretical Orientation**

Parents and parental surrogates are often the primary medical caregivers for children and serve as conversational proxies (i.e., speak on behalf of the child) during healthcare interactions (Goldsmith, Wittenberg-Lyles, Ragan, & Nussbaum, 2011). Parents have a significant role in the treatment period of a child's chronic health condition. Many pediatric chronic conditions result in acute care needs from severe episodes of the condition that require increased hospitalizations and doctors visits, as well as extended stays for in-patient treatments (Darcy, Björk, Enskär, & Knutsson, 2014; Schuster, Chung, & Vestal, 2011). When a child faces hospitalizations or ongoing treatments, parents may need to additionally adapt and cope with stress related to the treatments (Kazak & Barakat, 1997). This is because hospitalizations of children living with chronic conditions can be a traumatic and stressful experience that results in significant anxiety and distress for parents (Barakat & Alderfer, 2011). Therefore, understanding parental caregivers' experiences as they traverse the treatment period of a child's chronic condition is important because a parent's psychosocial adjustment is a significant indicator of a child's health status (Page et al., 2012; Rabineau, Mabe, & Vega, 2008; Steele, Aylward, Jensen, & Wu, 2009), a child's adherence to medical treatments (Maikranz, Steele, Dreyer, Stratman, & Bovarid, 2007; McGrady, Laffel, Drotar, Repaske, & Hood, 2009; Streisand, Braniecki, Tercyak, & Kazak, 2001), and a family's functioning and adjustment to a child's condition (Drotar, 2013; Logan & Scharff, 2005; Palermo & Chambers, 2005).

Although the available research evidence is far from conclusive, the reported impact of parent functioning on child and family adjustment does support the need to

target parents in family-based interventions for children living with chronic conditions. Researchers suggest that feasible and effective interventions for parents should include issues, such as addressing parents' uncertainties and enabling them to be agents of hope for their child (e.g., Jordan, Eccleston, & Osborn, 2007; Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009). Although many factors co-exist within the larger, complex, and multi-faceted process explaining why parents' adaptation to pediatric chronic diagnoses is positive or negative (Mussatto, 2006), uncertainty, hope, and hopelessness are regarded as three critical clinical constructs (Carlson, 2002; Farran, Herth, & Popovich, 1995) that influence parents' coping and adjustment to adaptations from caregiving responsibilities (e.g., Dillard & Carson, 2005; Kerr & Haus, 2014; Truitt, Biesecker, Capone, Bailey, & Erby, 2012). Further, uncertainty, hope, and hopelessness are considered to be related concepts (Duggleby, Williams, Wright, & Bollinger, 2009), and this potential relationship is delineated in theories such as uncertainty management theory (Brashers, 2001; Parrott, Peters, & Traeders, 2012). However, other scholars believe that these concepts are more dynamic than accounted for in these theories (e.g., Baxter, 2011; Thompson, 2011).

Uncertainty, hope, and hopelessness are also understood as being inherently interpersonal (Dillard & Carson, 2005; Elliott & Olver, 2002; Kirk, Kirk, & Kristjanson, 2004; Salmon, Hill, Ward, Gravenhorst, Eden, & Young, 2012) and based on external factors, such as information-seeking or conversations with other people (Verhaeghe, van Zuuren, Defloor, Duijnste, & Grypdonck, 2007a, 2007b). However, a dearth of research remains about parents' meanings and interactions as they experience uncertainty, hope, and hopelessness, and how communication with others (e.g., their child living with the

chronic condition, other family members, parents of other children with chronic conditions, healthcare professionals, friends) and communicative behaviors (e.g., information-seeking) may contribute to their social constructions of uncertainty, hope, and hopelessness. Most previous research focuses on the psychological elements contributing to parents' uncertainty, hope, and hopelessness, and/or identifies themes and does not consider the potential relationships among the themes that may explain the process of how parents' uncertainty, hope, and hopelessness is socially constructed. Therefore, studying parents' talk about their experiences with uncertainty, hope, and hopelessness, as they continue to manage their child's treatment is one way to glean this important information and develop a tentative, substantive theory explaining this process. This knowledge can increase sensitization to the needs of parents among specialists and multidisciplinary teams, and guide current and future services for families that improve clinical care.

### **Significance of Studying Parents' Uncertainty**

Learning how to effectively manage the caregiving role is a complicated and ongoing process for parents' that produces uncertainty throughout a child's diagnosis and treatment (Mishel, 1990; Oprescu, Campo, Lowe, Andsager, & Morcuende, 2013; Zaidman-Zait & Jamieson, 2007). Parental states of uncertainty are likely to fluctuate during a child's health trajectory (e.g., changes in prognosis). In response to the continuous uncertainties, parents may enact a variety of communication behaviors, which are often influenced by individual appraisals and preferences towards health and illness (Brashers, 2001). This is because different stressors during illness evoke various emotional and cognitive reactions that, in turn, influence a person's preferences for

communicating and responding to uncertainty and stress (Weber & Haunani Solomon, 2011). For example, Dillard and Carson (2005) found that parents have a range of reactions to uncertainty after a positive newborn screening for cystic fibrosis.

Specifically, some parents seek information to reduce uncertainty about a child's disease and procedures associated with it, while others avoid information in order to maintain hope and positive beliefs about their child's condition. Information avoidance may reflect a parent's desire to sustain current levels of uncertainty (Brashers, Goldsmith, & Hsieh, 2002). Given this variability, predicting which information strategy is most useful is not as meaningful as determining why certain information behaviors are utilized and considered more effective for managing uncertainty and maintaining hope (Brashers et al., 2002).

### **Significance of Studying Parents' Hope and Hopelessness**

Similar to uncertainty, parental hope is a highly variable concept that affects parents' adaptation to a child's diagnosis and is shown to positively influence parents' abilities to buffer stress and effectively cope (Barrera, D'Agostino, Gammon, Spencer, & Baruchel, 2005; Barrera et al., 2013; Herth, 1993). That is why hope has been identified as a key psychosocial resource for family caregivers of chronically ill individuals (Borneman, Stahl, Ferrell, & Smith, 2002; Duggleby et al., 2009; Duggleby et al., 2010; Herth, 1993). Throughout the trajectory of a child's chronic condition, parents' hope and hopelessness is shown to oscillate (Barrera et al., 2013) or move in a stepwise progression (Verhaeghe et al., 2007a). Often, parents' hope and hopelessness is influenced by external factors, such as a child's current health state, parents' trust in the physician and health care team, and a family's economic condition (Kylma & Juvakka,

2007). Hope may also influence parents' communication behaviors and responses to uncertainty. For example, within uncertainty management theory (UMT; Brashers, 2001), an individual's desire to maintain hope is typically associated with information avoidance or information control (Barbour, Rintamaki, Ramsey, & Brashers, 2012; Brashers, Neidig, Cardillo, et al., 1999; Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown, 2011; Parrott et al., 2012). These communication strategies proffer a more comforting way for patients and their caregivers to manage uncertainty and maintain hope (Brashers, Neidig, Haas, et al., 2000; Brashers, Neidig, & Goldsmith, 2004; Gill & Babrow, 2007).

Despite scholars burgeoning interest in understanding hope in response to uncertainty and adverse circumstances, such as the management of pediatric chronic conditions, the treatment period of many of these conditions remains relatively understudied (Barrera et al., 2013; da Silva, Jacob, & Nascimento, 2010; Field & Behrman, 2003). Studying parents' experiences during a chronically ill child's treatment is important because this period typically results in parents' heightened uncertainty and negative emotions, such as hopelessness, from having to make daily adjustments to living (Björk, 2008; Melnyk, Feinstein, Moldenhouer, & Small, 2001). Further, parents' resources are likely to become more exhausted as the condition persists and treatment ensues (Lavee & May-Dan, 2003). Most of the research on parental caregivers' experiences is from pediatric oncology parents, with the majority of that research conducted during a child's diagnostic stage (e.g., Bally et al., 2014; Barrera et al., 2013; Björk, 2008; Björk, Nordström, & Hallström, 2006; De Graves & Aranda, 2008). It is likely that uncertainty, hope, and hopelessness are central to parental caregivers experiences with children diagnosed with a variety of pediatric chronic conditions.

Further, these concepts may also be more salient during a child's treatment period.

Because uncertainty, hope, and hopelessness are often socially constructed from external factors (i.e., information and interactions with medical providers; Davis, 2005; Dillard & Carson, 2005; Elliott & Olver, 2002; Kirk et al., 2004; Salmon et al., 2012; Verhaeghe et al., 2007a, 2007b), talk and communication behaviors (i.e., information-seeking) are likely to be a part of the process. Subsequently, understanding parents' experiences with uncertainty, hope, and hopelessness, its meanings, and processes that inform their social constructions about these concepts serve as the impetus for conducting this dissertation research.

### **Rationale for the Use of Qualitative Methods**

Given the potential variability across parents' responses to uncertainty, hope, and hopelessness, as well as the potential for multiple factors influencing parents' responses, qualitative research is a well-suited approach for the study. Qualitative methods allow for understanding the multiple realities shaped by the interplay of social forces, cultural expectations, personal experiences, and knowledge (Creswell, 2007; Denzin & Lincoln, 2003; du Pré & Crandall, 2011). In this constructivist philosophical approach, a researcher uses inductive reasoning to extract and interpret the meanings and experiences from complex phenomenon, in this case examining parents' social constructions of uncertainty, hope, and hopelessness while managing their child's treatment for a chronic condition.

One way to learn more about these meanings and experiences is through in-depth interviews, which are guided conversations that allow researchers to elicit participants' experiences, perceptions, and narratives in their own words (Donovan, Miller, &

Goldsmith, 2014; Noller & Feeney, 2004). Thirty-five parents of children receiving ongoing medical or pharmacological treatment for a complex chronic condition were interviewed about their caregiving experiences, specifically focusing on parents' uncertainty, hope, and hopelessness. During the interviews, I asked parent's questions about their experiences and how conversations with other people (e.g., family, friends, health care team) and different communication behaviors (e.g. information seeking on the Internet) were a part of that experience. In analyzing the interview transcripts, I utilized a grounded theory approach (Charmaz, 2006; Strauss & Corbin, 1990) and constant comparative methods (Lincoln & Guba, 1985) to identify patterns and interrelationships among the emerging concepts and themes.

**Grounded theory.** Grounded theory is a research approach or method that utilizes inductive analyses (i.e., patterns, themes, and categories emerge naturally from the data) by exploring common experiences across individuals to develop a theory that is grounded within the data (Bowen, 2006; Corbin & Strauss, 2008; Creswell, 2007; Glaser & Strauss, 1967; Strauss & Corbin, 1990). The theory is generated by themes (i.e., concepts indicated by the data that are identified as common and significant; Morse & Field, 1995) that capture the essence of meaning or experience drawn from varied situations and contexts. Consistent with other types of qualitative research (e.g., thematic analysis, discourse analysis), a grounded theory warrants researchers to discover, understand, and interpret what is happening in the research context, as opposed to developing a priori hypotheses or preconceived notions. Researchers utilize grounded theory when current existing theories fail to address the problem or theory generation is needed to examine an action, process, or interaction (Creswell, 2007). Further, this

method is particularly useful in understanding topics when a paucity of research exists (Bally et al., 2013; Kars, Duijnste, Pool, van Delden, & Grypdonck, 2008). In this case, there is limited theoretical evidence explaining how parents talk about uncertainty, hope, and hopelessness while caregiving for their children with chronic conditions, and how communication behaviors may contribute to parents' social constructions of these concepts. Thus, a grounded theory is a suitable method to approach data collection and analysis.

It should be noted, however, that there is great diversity in how a grounded theory is construed, including “1) an empirical generalization, 2) a category, 3) a predisposition, 4) an explication of a process, 5) a relationship between variables, 6) an explanation, 7) an abstract understanding, and 8) a description” (Charmaz, 2006, p. 133). This debate also transcends into how to perform a grounded theory study. For some grounded theorists, sensitizing concepts (i.e., background ideas that inform the overall research problem; Charmaz, 2003) may be used in the development of a grounded theory to lay the foundation for the analysis of research data or examine substantive codes with a view to developing thematic categories (Bowen, 2006). Sensitizing concepts are “those background ideas that inform the overall research problem” and “provide starting points for building analysis” (Charmaz, 2003, p. 259). Many researchers view sensitizing concepts as interpretive devices that make it possible to attend to the important features of social interaction or guidelines for research in specific settings (Blumer, 1954; Bowen, 2006; Glaser, 1978; Padgett, 2004; Patton, 2002). Finally, because sensitizing concepts are naturally embedded within disciplinary emphases and perspectival proclivities (Charmaz, 2003), qualitative research often “begins with such concepts, whether

researchers state this or not and whether they are aware of them or not” (Gilgun, 2002, p. 4).

In conducting the dissertation, uncertainty, hope, and hopelessness were the three sensitizing concepts guiding data collection and analysis of parents’ interview transcripts. The specific focus on these three concepts was determined after thoroughly reviewing existing literature on the experiences of parental caregivers for children living with chronic conditions, as well as completing over one year of participant observations at the Ronald McDonald House Charities Eastern Wisconsin (RMHC)<sup>1</sup>. The salience and need to further understand parents’ uncertainty, hope, and hopelessness was evident across these sources, and seemed to underpin parents’ management of their child’s chronic condition.

It is important to consider that whereas sensitizing concepts might alert researchers to some important concepts, they also might direct attention away from other concepts present in the data (Gilgun, 2002). In any case, the ultimate survival of a sensitizing concept “depends on where the data take us; emergent concepts may supplement or displace them altogether” (Padgett, 2004, p. 301). Therefore, maintaining an open perspective, even while using sensitizing concepts, is critical when conducting a grounded theory analysis because it upholds modifiability (i.e., the researcher’s flexibility to alter the emerging or established analysis as conditions change or further data is gathered; Glaser, 1978). In this dissertation, I ensured modifiability by using a semi-structured interview guide, in which questions were adapted to parents’ responses. I also remained open to correction and change when engaging in the concurrent processes of

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<sup>1</sup> RMHC is an international non-profit organization that provides services (i.e., housing, food, therapy programs) for families with children hospitalized for medical treatments.

data collection and analysis. As the grounded theory developed, I used theoretical sampling (i.e., selection of participants dependent on elaborating and refining categories in the emerging theory; Charmaz, 2003, 2006) to interview parents in more focused interviews that attended to the development of the categories and processes within the emerging theory. In fact, focusing on parents with children diagnosed with complex chronic conditions evolved through the concurrent processes of data collection and analysis.

### **Purpose of Dissertation**

The psychosocial similarities across most pediatric chronic conditions (Kepreotes, Keatinge, & Stone, 2010; Nabors et al., 2013) warrants the need to examine parents' experiences with caregiving for children across a spectrum of chronic conditions in order to better serve a broader range of families. Thus, the purpose of this dissertation was to examine parents' talk about uncertainty, hope, and hopelessness as their chronically ill child(ren) received ongoing medical or pharmacological treatments. A communication approach to understanding the social construction of parents' uncertainty, hope, and hopelessness is relevant given that communication is regarded as a dynamic process (Goldsmith, 2001, 2004) that creates and shapes social meaning (Donovan-Kicken, Tollison, & Goins, 2012; Nurmi & Stieber-Roger, 2012) and provides structure for understanding the chronic illness experience (e.g., Caughlin et al., 2011; Donovan-Kicken, Tollison, & Goins, 2011). The final product is a grounded theory that will serve health researchers and clinicians in building a more sophisticated understanding of parents' experiences with uncertainty, hope, and hopelessness. Family-based interventions may benefit from this knowledge as current interventionists seek to assist

parents in managing uncertainty and constructing hope (e.g., da Silva et al., 2010).

### **Research Questions**

Two research questions guide the specific objectives of the dissertation:

RQ1: What are the processes affecting parents' meanings and social constructions of uncertainty, hope, and hopelessness?

RQ2: How does parents' talk inform a tentative, substantive theory explaining how parental caregivers experience uncertainty, hope, and hopelessness while managing the treatment period of their child's complex chronic condition?

### **Outline of Dissertation Chapters**

The dissertation is divided into five chapters and an appendix section. This first chapter provided a brief introduction including: (a) a statement of the problem, (b) research on parental caregivers, (c) the importance of focusing on parents' uncertainty, hope, and hopelessness, (d) the rationale for using qualitative methods and in particular a grounded theory approach, and (e) the two research questions guiding the study. Chapter two provides a comprehensive review of relevant literature<sup>2</sup> addressing the role of the family caregiver during chronic illness, with a particular emphasis on the significant role of parental caregivers for children living with chronic health conditions. I then address the need to focus on parents' uncertainty, hope, and hopelessness, and present previous

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<sup>2</sup> The proper role of a literature review for a study that utilizes inductive processes is to be embedded within the Discussion Chapter, since the review is to evolve simultaneously with the concurrent processes of data collection and analysis (Creswell, 2007). In this section, the study's results may be interpreted and integrated within previous literature. However, as Charmaz (2004) proposes, the review of previous literature may be presented prior to the findings so as to produce initial information that identifies broad areas of inquiry. In line with this thinking, Chapter 2 provides points of departure that were considered at the beginning of the study, including information that delineated areas of inquiry and guided the recruitment of study participants. Literature that is more pertinent to the actual results of the study is demarcated in the Discussion chapter (see Chapter 5).

research on definitions and theoretical tenets about these concepts. In addressing the limitations of previous research, I identify the need to examine parents' talk about these concepts to further understand their social constructions of uncertainty, hope, and hopelessness. The third chapter includes a description of the research methods including: selection of participants, demographic information, the forms of data collection, process for data analysis, my researcher positionality, the validation of strategies used to ensure the validity and reliability of the findings, and potential ethical issues. In chapter four, I present the results from the open, axial, and selective coding. Descriptive quotes from the interview transcripts and an illustrative model depicting the findings is advanced. The fifth chapter expands upon the results of the study by way of discussion, implications for theory development and practice, limitations and strengths of the study, directions for future research, and final conclusions. The appendices includes copies of the semi-structured interview protocol and survey, recruitment flyer, two tables reporting the categories and themes, as well as the demographic information from the parents interviewed and a copy of the grounded theory model.

## **Chapter 2: Review of Literature**

The dissertation informs efforts at family-based interventions by examining parents' talk about uncertainty, hope, and hopelessness as a child receives medical or pharmacological treatment for a complex chronic condition. This section includes previous research that helps to: (a) establish the importance of family caregiving during chronic illness, particularly the significance of parental caregivers for children living with chronic health conditions, (b) the salience of uncertainty, hope, and hopelessness in the parental caregiver experience, and (c) the need to examine parents' talk in order to understand their communication behaviors that may contribute to their social constructions of uncertainty, hope, and hopelessness. This knowledge may advance current family-based interventions that assist parents with managing uncertainty and enabling them to be agents of hope for their child and other family members (Jordan et al., 2007; Palermo et al., 2009).

### **Family Caregiving during Chronic Illness**

Chronic illness is a contextual family experience in which the illness experiences of one family member influence the entire family system (Miller & Caughlin, 2011; Revenson, 2003; Roy 2006). Therefore, effectively managing and coping with any chronic health condition cannot be accomplished without taking into consideration the patient's family and their experiences (Pecchioni & Kelley, 2011; Strauss & Glaser, 1975; Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010). Family members have a significant role as a caregiver. Traversing the illness experience requires family members to navigate healthy and risky behaviors, as well as encounter difficult health experiences such as hospitalization or death (Pecchioni & Keeley, 2011). During these

health events, it is common for family members to be directly or indirectly involved (e.g., making medical decisions, administering treatments at home, conducting online research about the health issue), and this involvement increases when chronic health issues surface.

Family caregiving during chronic illness is often negotiated or influenced by communication. Caring for an ill family member involves the provision of emotional support (e.g., offering assurances and encouragement) as well as instrumental care (e.g., taking loved one to a doctor's appointment; Thoits, 1985). The ways that families provide support and discuss health topics are shaped by many factors, including socioeconomic status, gender roles, ethnic background, religion, family communication patterns, and family cultural norms (Pecchioni & Keeley, 2011; Wittenberg-Lyles et al., 2010). Other factors such as relationship quality, topic orientation (i.e., an individual's understanding of the illness), and type of illness (i.e., whether the illness is stigmatized) also affect family illness conversations and the provision of care (Bauer, 2011).

Typically, adverse psychological reactions arise for individuals and families when a person is diagnosed with a chronic, severe, or life-threatening illness. This is because the onset of a chronic health condition, particularly when it is severe or life-threatening, is often a negative life event that changes family dynamics and introduces immediate and long-term stress (Roy, 2006; Rolland, 1987, 1999). In response to the chronic condition, family members must learn to manage treatment plans, provide day-to-day care, adjust to new family roles, and potentially consider end-of-life care. These responsibilities require changes and transitions that families must learn to navigate as they traverse the illness course. When dramatic changes in an individual's condition occur (e.g., intensive

treatment regimens or hospitalizations), family members must incur substantive adaptation and reassessment to manage heightened stressors and caretaking demands (Miller-Day, 2011). These demands affect family members' time, energy, financial resources, and emotional support (Albrecht & Adelman, 1987). Thus, balancing these competing demands becomes a daunting challenge for many family caregivers (Boss, 2008).

The daily care and emotional support proffered by families may be associated with positive health outcomes, such as better coping, for both the patient and other family members (Burlison & MacGeorge, 2002; Pecchioni, Thompson, & Anderson, 2006). However, because taking care of a sick family member is often a stressful experience and most family networks are not composed of trained professionals, many families are ill-equipped to be sufficient caregivers for the patient (Pecchioni et al., 2006). Part of this problem arises from the limited support that families receive post-diagnosis. In general, supportive resources are likely to become more exhausted or depleted as the condition persists and treatment ensues (Lavee & May-Dan, 2003). For example, families with an individual diagnosed with multiple sclerosis report feeling a range of negative emotions (e.g., stress, guilt, frustration, sadness, fear) because of limited social support; these emotions are exacerbated as their family member's condition persists (Bowen, MacLehose, & Beaumont, 2011).

Ineffective or insufficient support adversely affects relationship quality between family caregivers and the patient (Adams, 2008), even for the strongest family relationships (Miller-Day, 2011). For example, breast cancer is often a challenging, tense experience for mothers and daughters as both individuals attempt to manage each other's

emotional changes, social alterations, and physiological transformations (Fisher, 2011). Similarly, Alzheimer's disease affects the entire family unit as anxiety ripples throughout the family system (Hipper, Catona, & Nussbaum, 2011) and heightens family tensions and conflict (Szinovacz, 2003).

Families experience ongoing emotional hardships because chronic health conditions involve broader aspects of a person's life (e.g., home, work) that impact daily routines. To illustrate the pervasive nature of chronic conditions in families' lives, Corbin and Strauss (1985, 1988) identified three types of work that are performed when a family member is diagnosed with a chronic health condition: illness work (i.e., managing the chores associated with the health condition or disability, such as receiving medical treatments or monitoring diet), biographical work (i.e., accepting what the condition entails for identity and future plans), and everyday-life work (i.e., daily tasks that people tend to do ordinarily, such as paying bills and managing the household; Corbin & Strauss, 1985, 1988). Recently, Donovan-Kicken et al. (2012) added a fourth line of work that includes communication work. Here, managing health-related information is considered to be another type of work that is a demanding and effortful task that involves active message design (e.g., preparing positive messages in advance in order to best manage emotions during a challenging or difficult conversation about illness; Donovan-Kicken, Tollison, & Goins, 2011, 2012). Regardless of the type of work performed by families, all of this work occurs alongside the other tasks that are required for families to continue living "with more or less success despite the illness" (Corbin & Strauss, 1988, p. 10).

### **Family Caregiving during Pediatric Chronic Illness**

The work required of families during a chronic health condition is magnified

when a child is diagnosed because of the dependent nature of children on family caregivers and the likelihood of severe episodes occurring that require high-intensity acute care (Darcy, Björk, et al., 2014; Schuster et al., 2011). The term “pediatric chronic illness” refers to a medical condition with the following criteria: (a) the onset occurs between the ages of 0 and 18; (b) the diagnosis is based on medical scientific knowledge, (c) the illness is not (yet) curable, and (d) the illness exists for a minimum of three months, or three episodes have occurred within the last year (van der Lee, Mokkink, Grootenhuys, Heymans, & Offringa, 2007). Common pediatric chronic illnesses that fit within this definition include: asthma, diabetes mellitus, congenital heart disease, juvenile rheumatoid arthritis, cystic fibrosis, and mental illness (e.g., eating disorders, obsessive-compulsive disorder). An increasing number of children are also living with genetic, chromosomal, and metabolic conditions, such as Down Syndrome, hemophilia, and G6PD deficiencies. Today, approximately 20% of North American children ages 0 to 17 years are currently living with chronic health conditions (Boyse, Boujaoude, & Laundy, 2012; Branstetter, Domain, Williams, Graff, & Piamjariyakul, 2008), and 13.9% of children ages 0 to 17 years have special health care needs (e.g., learning disabilities, developmental delays; Children and Adolescent Health Measurement Initiative, n.d.). Co-morbidity is common among children with pediatric chronic conditions, with 29.1% of children reporting the presence of three or more health conditions (Children and Adolescent Health Measurement Initiative, n.d.).

The 20 million children and their families affected by pediatric chronic conditions experience a great deal of uncertainty and distress as they attempt to manage the medical condition with a child’s emotional, behavioral, and developmental issues (Mussatto,

2006; Patterson, Holm, & Gurney, 2004). Post-diagnosis, families of chronically ill children must make major life adjustments to learn how to coordinate treatment and medical appointments with the rigors of daily life (e.g., finances, career, other children; Fritsch, Overton, & Robbins, 2011). The increased potential for hospitalizations to occur that requires treating severe episodes of the health condition or administering in-patient treatments (e.g., chemotherapy) can be a traumatic and stressful experience for families (Barakat & Alderfer, 2011). In these instances, parental caregivers may need to adapt and cope with stress related to the child's treatment first, before they continue adapting to the medical illness itself (Kazak & Barakat, 1997). Thus, chronic illnesses and their treatments present children and their families with significant sources of stress that can contribute to psychosocial adjustment problems.

A significant part of effectively managing a child's condition and treatment is family interrelationships with one another and members within one's support network (e.g., extended family, medical professionals; Foster, Whitehead, Maybee, & Cullens, 2013). This is why parents with multiple children often turn to their other children for assistance in care responsibilities for the sick child (Branstetter et al., 2008). However, the collective nature of providing sufficient care for a child diagnosed with chronic illness is negatively associated with various areas of family functioning, including the physical and mental health of all family members, as well as familial closeness (Schneider, 2005).

**Parents as primary caregivers during pediatric chronic illness.** Parents are particularly affected by the diagnosis and treatment of a child's chronic condition. After receiving their child's diagnosis, parents often wrestle with the uncertainty about their

child's condition and prognosis (Melnik et al., 2001). Receiving the diagnosis, in particular, is regarded as an extreme strain that puts parents into shock (McGrath, Kail-Buckley, & Philips, 2007). Parents immediately start striving to survive using information and other supportive resources as a means to reduce the chaos they are experiencing (Björk, Wiebe, & Hallström, 2005). This is why information has been described as a critical part of the provision of care (Björk et al., 2005; Kerr, Harrison, Medves, Tranmer, & Fitch, 2007; Ljungman et al., 2003; McGrath et al., 2007; von Essen, Enskär, & Skolin, 2001). During the treatment period, parents struggle with the chronic burden of care and may experience recurrent and chronic sorrow as they watch their child struggle to achieve developmentally-appropriate skills (e.g., learning to walk, receiving a drivers license, attending school). If the condition requires hospitalization or increased medical services, additional stress and demands may be placed on parents that create a dramatic reconfiguration of their roles, in which a child's medical needs engulf a parent's existence (Klick & Ballantine, 2007). Further, parents may experience uncertainty and negative emotions from having to make daily adjustments to normal living because of treatment regimens and increased hospitalizations (Barakat & Alderfer, 2011; Björk, 2008; Klick & Ballantine, 2007; Melnyk et al., 2001).

On average, parental caregivers spend an extra 30 hours per week tending to the needs of a child's chronic health condition (National Alliance for Caregiving & AARP, 2009). Parents may perform a multitude of complex tasks ranging from manual (e.g., tube feeding) to cerebral (e.g., coordinating appointments or juggling shift nursing schedules; Klick & Ballantine, 2007). These demands change parents' relationships with one another and foster an environment that is ripe with communication difficulties (da Silva

et al., 2010). Parental conflict over care is common (Meert, Briller, Myers Schim, Thurston, & Kabel, 2009) and poor communication negatively impacts a child's care and the family's quality of life. Further, supportive resources are likely to become more exhausted as a child's condition persists (Lavee & May-Dan, 2003).

The chronic burden of care associated with managing children's chronic health conditions has led many parents to report struggling with marital distress, work-related problems, and experience an overall negative socioeconomic impact due to the costs of medical treatments (Goodman, 2010; Kuhlthau, Kahn, Hill, Gnanasekaran, & Ettner, 2010; National Alliance for Caregiving AARP, 2009). In a recent survey, 40% of parental caregivers surveyed reported being in high-burden situations based on the level of care that was required from them (National Alliance for Caregiving & AARP, 2009). These problems affect both mothers and fathers who have reported experiencing physical health deterioration, including fatigue, headaches, irritability, anxiety, and stress (Board, 2004; Shudy et al., 2006). In sum, the rigorous demands of caregiving have led parents of children with chronic health conditions ranging from asthma to cancer to consistently report experiencing poor levels of health-related quality of life (i.e., how parents perceive the child's health impacting their physical and psychosocial functioning; Cohen, Vowles, & Eccleston, 2010).

### **Significance of Studying Parental Uncertainty, Hope, and Hopelessness**

A growing body of evidence supports the direct causal relationship between parent/family functioning, and a family's adjustment to pediatric chronic conditions (e.g., Drotar, 2013; Logan & Scharff, 2005; Palermo & Chambers, 2005). The current assumption that the severity of a child's condition is the primary predictor of long-term

parental adaptation must be augmented and redirected to emphasize the subjective experiences of parental caregivers (Mussatto, 2006). This is because adaptation to a child's chronic condition may be influenced by multiple intervening concepts (e.g., stress appraisals, resiliency, condition-related factors, social support, quality of life, communication; McCubbin, Thompson, & McCubbin, 1996; Mussatto, 2006) that all contribute to a family's psychosocial well-being. Further, understanding the subjective importance caregivers' attribute to their experiences provides important insights into sense-making and the social construction of health and illness. Parents' uncertainty, hope, and hopelessness have been identified as three critical clinical concepts (Carlson, 2002; Farran, Herth, & Popovich, 1995) that significantly affect parents' adaptations to their children's chronic conditions (Dillard & Carson, 2005; Kerr & Haus, 2014; Truitt et al., 2012).

**Parental caregivers' uncertainty.** Uncertainty is the "inability to determine the meaning of events and occurs in a situation where the decision maker is unable to assign definite values to objects and events" (Mishel, 1990, p. 256). Consistent with its definition, uncertainty often accompanies a perceived absence or loss of control over outcomes. In other words, uncertainty is not being able to predict the outcome of an event and is often linked to a perceived inability to affect the outcome (Bordia, Hunt, Paulsen, Tourish, & DiFonzo, 2004). The diagnosis of chronic health conditions in children is a prototypical event that may create a host of uncertainties for parents. The course of many pediatric chronic conditions is unpredictable and often involves complex and intrusive treatment regimens (Page et al., 2012), which adds to parents' initial uncertainties. Uncertainty occurs immediately upon diagnosis and persists during a child's treatment

period (Mishel, 1990; Oprescu et al., 2013; Zaidman-Zait & Jamieson, 2007). Parents' uncertainty is shown to increase when limited or negative information is received regarding their child's prognosis or the severity of his or her condition (Mishel, 1984).

Kerr and Haus (2014) identified five types of uncertainties that parents may experience during the diagnosis of their child's chronic condition: normalization uncertainty (i.e., parents' concerns over their child's future and ability to experience a "normal life"), information uncertainty (i.e., parents' concerns over receiving multiple medical opinions), orphan-illness uncertainty (i.e., parents' concerns about additional health risks when a condition is complex), parental proxy uncertainty (i.e., uncertainty surrounding medical decision-making and communication with others about the illness), and social stigma uncertainty (i.e., uncertainty pertaining to fear of social stigma due to the illness). Each type of uncertainty may impact broader aspects of children and families' lives (e.g., home, work).

The presence of different types of uncertainty among parental caregivers can result in negative emotions (e.g., worry, fear, stress) that may exacerbate original psychological symptoms (Holm, Patterson, Rueter, & Wamboldt, 2008) and lead to parents' poor psychological adjustment (Cohen et al., 2010; Liu & Yeh, 2010; Steele et al., 2009). In fact, maternal stress levels are more likely to increase when incomplete recovery is a likely outcome (e.g., chronic illness; Keller & Honig, 2004; Nicholson, 2004). Parents' responses to uncertainty have a direct impact on children's adjustment to their diagnoses (Rabineau et al., 2008), and parents' negative responses to uncertainty may increase children's depressive symptoms (Page et al., 2012; Steele et al., 2009) and negatively affect children's adherence to medical treatments (Maikranz et al., 2007;

McGrady et al., 2009; Streisand, Braniecki, Tercyak, & Kazak, 2001). Therefore, it is important to understand how parents talk about uncertainty and the outside factors influencing their behaviors to effectively manage uncertainty.

There are qualitative differences in the way that parents narrate and manage the uncertain and stressful experiences with having a chronically ill child. Drawing on Frank's (1995) typology of illness narratives, parents of children with congenital heart disease are more likely to adopt a protracted restitution narrative (i.e., individuals discuss departure from health to condition and back to health), while parents of youth with cystic fibrosis more frequently discuss elements of chaos (i.e., individuals are so consumed by condition that stories are never resolved) and quest narratives (i.e., body and self are profoundly transformed through the condition; Moola, 2011). Examining these different narratives allows scholars to understand individuals' sense-making and coping with chronic disease (Koenig Kellas & Trees, 2013; Manoongian, Harter, & Denhem, 2010). Parents not only narrate about their uncertainty differently, but they also respond to uncertainty in different ways. Dillard and Carson (2005) found that after a positive newborn screening for cystic fibrosis, some parents sought information to reduce uncertainty about the disease and procedures associated with it, while other parents avoided information. Information avoidance allowed parents to sustain their preferred level of uncertainty as a way to better cope with their child's diagnosis.

In line with this knowledge about the variability across uncertainty management behaviors and talk about uncertainty, recent developments in psychotherapy techniques have proposed a shift from reducing parents' uncertainty about their child's pediatric chronic illness to teaching parents how to effectively manage uncertainty and make

behavioral changes consistent with personal values and goals (i.e., Hayes, Luoma, Bond, Masuda, & Lillis, 2006). This approach allows parents to best cope with the inherent risks and ambiguity associated with myriad pediatric chronic conditions. In addition, parents' acknowledgement of the ubiquitous nature of uncertainty during pediatric chronic illness allows them to achieve greater adaptability throughout their child's health trajectory and has been referred to as growth through uncertainty (Mishel, 1990; Mishel & Clayton, 2008) or uncertainty adaptation (Brashers, 2007). Similarly, other scholars have found that parents who adopt this approach toward uncertainty are able to embody a type of resilience (i.e., ability to maintain a stable equilibrium) in the face of loss and trauma (for a review see Bonanno, 2004; Bonanno, Brewin, Kaniasty, & La Greca, 2010).

**Parental caregivers' hope.** As parents attempt to manage the uncertainty associated with caring for their chronically ill child, they must become a "bearer of hope" for the entire family (Verhaeghe, DeFloor, van Zuuren, Duijnste, & Gryphonck, 2005). Hope—the feeling of yearning for an outcome that the odds do not favor—is an emotional fuel that motivates individuals to sustain efforts to manage stressors, such as uncertainty, and act in pursuit of their goals (Lazarus, 1991). Hope is an integral part of parents' coping with their child's chronic diagnosis (Reder & Serwint, 2009; Verhaeghe et al., 2005; Verhaeghe et al., 2007a), particularly if the prognosis is severe or life-threatening (Engström & Söderberg, 2004). Parental caregivers for children with pediatric chronic conditions have defined hope as an "essential, powerful, deliberate, life-sustaining, dynamic, cyclical process that [i]s anchored in time; [i]s calming and strengthening; and provides inner guidance through the challenging experience of

preparing for the worst and hoping for the best” (Bally et al., 2014, p. 363). In this case, parental hope is conceptualized as a multidimensional concept with an orientation toward life and future and is linked to a child’s disease progression, health status (Kylma & Juvakka, 2007), prognosis (Mack, Wolfe, Cook, Grier, Cleary, & Weeks, 2007), and future cure (De Graves & Aranda, 2008; Mack et al., 2007).

There are many other definitions, models, and conceptual frameworks that have been proffered about hope. Hope has been referred to many things including, an inner power (Herth, 1990) and a cognitive energy (i.e., thoughts) with pathways for achieving goals (Snyder, Hardi, Cheavens, Michael, Yamhure, & Sympson, 2000). The plethora of definitions results in a lack of precision about this concept (Kylma & Vehvevilainen-Julkunen, 1997). Nonetheless, most scholars understand hope to be an individual-based, future-oriented concept that sees beyond limitations toward dreams, possibilities, and desired goals (Kearney & Griffin, 2001; Snyder, 2002). Self-perception, individual motivation, and self-efficacy are considered critical variables that affect a person’s ability to remain hopeful (Snyder, 2000a, 2000b, 2002).

Functionally, hope has been identified as a key psychosocial resource for family caregivers (Borneman et al., 2002; Duggleby et al., 2009; Duggleby et al., 2010; Herth, 1993) because of its ability to buffer stress through positive emotions that facilitate effective coping (Herth, 1993; Goldsmith, Miller, & Caughlin, 2008; Mednick, Cogen, Henderson, Rohrbeck, Kitessa, & Streisand, 2007). In a meta-synthesis of 14 studies about family caregivers of patients diagnosed with different chronic conditions, Duggleby et al. (2010) found that a strong overall feeling of hope in the face of uncertainty has outcomes of increased feelings of control, decreased feelings of loss and

grief, and improved physical and psychosocial well-being.

Understanding hope in parents of children diagnosed with chronic conditions is of great value to health care professionals because parental hope is associated with quality of life and treatment outcomes. In particular, parental caregivers reporting high levels of hope tend to be more adaptive and able to cope with difficulties encountered during their child's chronic illness than parents reporting low hope (Horton & Wallander, 2001; Mednick et al., 2007). This is because parents often act out of a sense of hope for their child's restoration, and this hope can balance some of their grief and serve as a coping mechanism when caring for their children (Klick & Ballantine, 2007). For example, parents who are more hopeful are more likely than parents who are less hopeful to have more parental presence in neo-natal units, which is a strong predictor of greater infant recovery (Charchuk & Simpson, 2005). Hope has also influenced parents' medical decisions and choices for treatment (e.g., having a do-not-attempt resuscitation order; Feudtner et al., 2010), as well as their involvement in phase 1 clinical trials for incurable diseases (Barrera et al., 2005). In sum, hope can help parents absorb the initial crisis associated with having a chronically ill child, overcome the fear of the unknown, sustain their adaptation during the rigors of treatment, and prepare for an unknown future that may include a potentially fatal outcome (Roscigno et al., 2012; Samson, et al., 2009).

**Parental caregivers' hopelessness.** Parents' levels of hope typically decrease when a child is diagnosed with a chronic condition (Venning, Elliott, Whitford, & Honnor, 2007). This is because parents often live in a state of transitory hope as they watch the health condition deteriorate their child and experience loss from their child not achieving significant life and developmentally-appropriate milestones (e.g., not getting a

drivers license, not learning how to walk; Klick & Ballantine, 2007). During these events, many parents report experiencing hopelessness, in which current life conditions overwhelm available coping resources (Hill, Costellanos, & Pettita, 2011) and demoralization occurs (Clarke & Kissane, 2002). In seminal research on hopelessness, a lack of control has been identified as the central factor leading to hopelessness (e.g., Abramson, Metalsky, & Alloy, 1989). Chronic exposure to uncontrollable stressors, such as the challenges with effectively treating children's complex chronic conditions, leads to a belief in the impossibility of making a change and a resultant loss of hope (Walker, 2001). Similar to hope, parents' feelings of hopelessness may be influenced by different external factors, including the type of relationship (Salander, 2002), individuals' active appraisals to the information they hear (Salander, Bergenheim, & Henriksson, 1996), and perceptions of the immediacy or salience of uncertainty (e.g., whether the uncertainty is derived from a macro-issue v. micro-issue; Afifi, Afifi, Robins, & Nimah, 2013). Thus, the mere presence of chronic uncertainty does not automatically correlate with feelings of hopelessness, even in dire situations (e.g., Palestinian refugee camp; Afifi et al., 2013).

### **The Interpersonal Nature of Uncertainty, Hope, and Hopelessness**

Parental uncertainty, hope, and hopelessness are not only psychological, but are also considered to be inherently interpersonal and influenced by external factors. These external factors (i.e., outside the person) may include: (a) *level of support from others* (Bland & Darlington 2002; Borneman et al., 2002; Duggleby et al., 2009; Herth, 1993; Holtslander & Duggleby, 2009; Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2003), (b) *critical events surrounding a family member's health condition* (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Herth, 1993; Kylma et al., 2003), (c)

*relationship with family members* (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Kylma et al., 2003), and (d) *information about a patient's condition* (Bland & Darlington, 2002; Duggleby et al., 2009). Often, parental caregivers' uncertainty, hope, and hopelessness are determined by physician trust (Salmon et al., 2012), conversations with other people (e.g., other family members; Barrera et al., 2013; Davis, Mayo, Piecora, & Wimberley, 2013; Lin, Yeh, & Mishel, 2010), as well as information seeking (e.g., searching medical information online; Brashers, 2001; Verhaeghe et al., 2007a; 2007b). Altogether, these external factors contribute to how parents' uncertainty, hope, and hopelessness are experienced, and these experiences have been shown to affect their specific hopes (e.g., hope for a cure, or hope for a peaceful death) as well as subsequent interactions with others (e.g., their child, other parents, their partner; Barrera et al., 2013; Duggleby et al., 2010).

The interpersonal nature of uncertainty, hope, and hopelessness derives from the fact that hopeful information is exchanged amidst the uncertainties pertaining to a child's chronic condition, treatment regimen, and quality of life. The relationship between uncertainty and hope/hopelessness is reciprocal. While hope and hopelessness influences uncertainty, uncertainty also influences hope and hopelessness (Verhaeghe et al., 2007a, 2007b), such that uncertainty is often the backdrop in which the possibility of hope is situated (Duggleby et al., 2010). For example, in uncertainty management theory hope partially mediates the relationship between uncertainty and communication preferences (Brashers, 2001, 2007; Brashers, Haas, & Neidig, 1999; Olver & Elliott, 2002; Parrott et al., 2012). That is to say, during situations of uncertainty, individuals' appraisals of uncertainty as an opportunity rather than a burden may result in them enacting certain

behaviors to maintain hope. These behaviors typically include information avoidance (Brashers, Neidig, Cardillo, et al., 1999) or information control (Brashers, 2001; 2007; Barbour et al., 2012; Brashers, Neidig, Haas, et al., 2000; Brashers et al., 2004; Caughlin et al., 2011; Goldsmith et al., 2008; Parrott et al., 2012; Truitt et al., 2012). For example, Barbour et al. (2012) found that family members and friends report avoiding information as a way to maintain or increase hope when an individual's health prognosis is uncertain. Similarly, other researchers have found that maintaining or increasing uncertainty through conversation avoidance allows family caregivers to maintain hope about an individual's prognosis (Caughlin et al., 2011; Goldsmith et al., 2008; Miller, 2014; Parrott et al., 2012).

Typically, the provision of realistic information in a supportive, collaborative environment is considered to be more health-nurturing and hopeful than avoidant behavior (Hagerty, Butow, Ellis, & Tattersall, 2005), particularly for parents with children who have chronic conditions. Even in the midst of uncertainty, many parents desire to have open conversations with medical providers about hope (Kirk et al., 2004) and these conversations may establish parameters about what should be hoped for or against (Dillard & Carson, 2005; Elliott & Olver, 2002). For example, some researchers have found that parents of children living with cancer found more hope in making effective treatment decisions after receiving the full disclosure of prognostic and treatment information compared to instances where parents received limited information (Mack et al., 2007; Markward, Benner, & Freese, 2013). In fact, parents' desire for more information was even preferred over limited information when their child's condition was considered to be life-threatening. Similarly, Roscigno et al. (2012) found that even during

times of hopelessness, parents desired to discuss the full spectrum of information regarding their child's prognosis.

It is important to note that not all parents have the same information preferences (e.g., Dillard & Carson, 2005). In some instances, information avoidance has been shown to foster more hope (e.g., Brashers, Neidig, Haas, et al., 2000; Brashers et al., 2004). For example, Salmon et al. (2012) found that avoiding information about a child's longer-term care was critical for maintaining parental hope. Within the study, parents relied on oncologists to cushion information about long-term uncertainties so the parents could focus on their child's short-term milestones and remain more hopeful. In this case, the preservation of hope was not perceived as a denial of long-term outcomes, but rather by concentrating on short-term events regarding their child's treatment and avoiding discussions about the future, parents were able to more easily manage uncertainty and process their child's health condition in a way that they acknowledged to be meaningful and useful (e.g., life-affirming rather than death-denying; Elliott & Olver, 2002, 2007). Individual preferences towards avoidant behaviors and information control as a way to maintain and preserve hope have been identified across individuals experiencing persistent trauma or chronic uncertainty (e.g., Afifi et al., 2013; Parrott et al., 2012). In particular, researchers have found that care providers concerned with helping parents maintain hope and manage uncertainty may: (a) focus on immediate milestones and hurdles rather than more distant challenges, and (b) concentrate on positive and achievable treatment goals (Butow, Dowsett, Hagerty, & Tattersall, 2002; Shirado et al., 2013). For instance, physicians may refrain from disclosing key information in order to maintain hope in patients and caregivers (Foster et al., 2013; Klick & Ballantine, 2007;

Thompson, 2011). Thus, regardless of the communication behavior (i.e., information seeking or avoidance) hope influences how uncertainty is managed, typically in a way that is perceived to be more comforting for the individual and maintains a positive adaptation towards the chronic condition (Brashers, Neidig, Haas, et al., 2000; Brashers et al., 2004; Gill & Babrow, 2007).

However, for hope to lead to better outcomes (e.g., improvements in health, coping disease adjustment, positive social support elicitation), a collaborative discursive strategy among family members and medical providers is needed to balance honest hope (i.e., hope based on information that is accurate and complete; Davis et al., 2013; Verhaeghe et al., 2007a) with the reality of the prognosis (Fisher, Miller-Day, & Nussbaum, 2013; Roscigno et al., 2012). One type of discursive strategy is strengths-based language (i.e., focusing on positive attributes about an individual's resources and talents as a vehicle for positive change to help families manage a child's chronic condition; Davis et al., 2013). This type of future-oriented communication reframes health problems by reminding family members that they are not alone and that resources exist to help them manage their child's chronic condition. Discursive strategies, such as this, help families traverse the uncertainties associated with chronic conditions and prepare for negative circumstances, such as an imminent death (Shirado et al., 2013). Conversations that utilize these strategies are also shown to positively facilitate in parents' medical decision making (Markward et al., 2013). For example, if an exaggerated hope or a false sense of hope is discussed, parents are more likely to insist on aggressive medical treatments, even when such treatments cause additional suffering (e.g., pain, isolation, nausea, increased hospitalization) with little or no chance of success

(Baergen, 2006).

This line of research on the social construction of hope (i.e., Davis et al., 2013) and research from other scholars (i.e., Thompson, 2011; Baxter, 2011) begins to recognize that hope is richer, more challenging, and more consequential than a simple variable to be tested. Treating hope as a social and information-processing conduit or variable that explains or predicts the prevalence of certain uncertainty management behaviors (i.e., uncertainty management theory; Brashers, 2001) inadequately conceptualizes the complexity of caregivers' uncertainty, hope, and hopelessness, and the fact that the same health information that prompts feelings of hope may also incite hopelessness.

In an attempt to further examine the dynamic nature of hope, Barrera et al. (2013) advanced a model in which hope was identified as a push and pull concept where parents' hope oscillated between being tenacious and robust, and being tenuous and elusive. Parents' assessments of hope within this spectrum were dependent on external factors such as how a child was responding to treatment, as well as the larger psychosocial context comprised of facilitators and barriers to hope. Parents who focused on positive outcomes and experiences, reported higher levels of spirituality, and received more social support were found to be more hopeful than parents who did not have such experiences. Factors that challenged parental hope included awareness of negative outcomes, information overload, physical and emotional depletion, fear and uncertainty.

### **Advancing Knowledge on the Social Construction of Parents' Uncertainty, Hope, and Hopelessness by Analyzing Parents' Talk**

By positing that parents' hope is influenced by the larger psychosocial context,

which includes social support and other communicative behaviors (e.g., information seeking, negativity from other people, medical disclosures) during interactions with medical professionals and supportive networks, Barrera et al. (2013) convey the need to examine parents' communication and talk about hope as a way to understand its social construction for parental caregivers with chronically ill children. In an assessment of parents' hope, researchers must also study hopelessness and not just assume that a barrier to hope is synonymous with parents' feelings of hopelessness. Because hope and hopelessness are often situated within the backdrop of uncertainty (Duggleby et al., 2010), the relationships among these three concepts is an important consideration for examining the social construction process. After all, interpersonal communication is regarded as the primary antidote to uncertainty (e.g., Afifi, 2009), and hope and hopelessness may be situated within uncertainty (Duggleby et al., 2010). Thus, Barrera et al.'s (2013) conceptualization that uncertainty is a barrier to hope, may not be fully accurate as other researchers have found that uncertainty during pediatric chronic illness is inevitable and occurs throughout a child's diagnosis and treatment period (e.g., Björk et al., 2005; McGrath et al., 2007; Melnyk et al., 2001).

A particular focus on parents' talk is needed because individuals are part of a larger communicative infrastructure with each part of the system simultaneously affecting, and being affected by, the other (Afifi, Afifi, & Merrill, 2014). Social relationships, and the communication patterns that characterize them, have the power to significantly affect daily experiences, meanings, interactions, and practices related to the management of chronic illness (Nabors et al., 2013; Nurmi & Stieber-Roger, 2012). This is why analyzing talk and communication behaviors may provide important insights into

family functioning and how uncertainty, hope, and hopelessness affect parental caregivers of chronically ill children. Already, some scholars have noted the significance of communication in the social construction of uncertainty and hope (e.g., Afifi et al., 2013; Brashers, 2001; Barbour et al., 2012; Brashers, Neidig, Haas, et al., 2000; Brashers et al., 2004; Caughlin et al., 2011; Davis, 2005, 2012; Davis et al., 2013; Goldsmith et al., 2008). Other scholars have highlighted the important role that external factors, such as information seeking and the provision of social support, have on individuals' hope (e.g., Bland & Darlington 2002; Borneman et al., 2002; Duggleby et al., 2009; Duggleby et al., 2010; Herth, 1993; Holtslander & Duggleby, 2009; Kylma et al., 2003). However, an examination of all three related concepts (i.e., uncertainty, hope, and hopelessness), as well as the factors contributing to parents' social constructions of uncertainty, hope, and hopelessness as they manage treatments for their child's chronic condition has yet to be studied. Therefore, this dissertation proffers a distinct and novel contribution to previous research by analyzing the content and information discussed by parents about their experiences with uncertainty, hope, and hopelessness. This examination goes beyond acknowledging the mere existence of these concepts as themes describing the parental caregiving experience, and assesses the potential relationships among inductive categories pertaining to factors contributing to parents' social constructions of uncertainty, hope, and hopelessness. The acquired knowledge may clarify scholars understanding of parents' coping, sense-making, communicating, and managing of pediatric chronic conditions, as other scholars have found in different populations and settings (e.g., Davis et al., 2013; Thorne, Hislop, Kuo, & Armstrong, 2006).

**Relevant communication-based theories.** Presently, several communication-

based theories have been proffered to study family caregivers' talk and language during chronic health situations. Such theories include, but are not limited to, *relational dialectics theory* (e.g., Davis et al., 2013; Golish, & Powell, 2003; Golden, 2010; Kvigne & Kirkevold, 2003; Mirivel & Thrombe, 2010; Pawlowski, 2007), *uncertainty management theory* (e.g., Babrow & Kline, 2000; Brashers, Haas, et al., 1999; Brashers, Neidig, & Haas, et al., 2000; Brashers et al., 2004; Volkman & Silk, 2008), and *communicated narrative sense-making* (Koenig Kellas, Trees, Schrod, LeClair-Underberg, & Willer, 2010; Koenig Kellas, 2005; Koenig Kellas & Kranstuber Hortsman, 2015). Each of these theories originates from a social constructivist perspective, meaning that reality is determined by communication and language that is co-constructed by individuals, rich with meaning, and inherently linked to quality of life (Blumer, 1969; Goffman, 1959, 1963; Mead, 1959). Below is a brief overview of these theories and frameworks, as well as the specific research studies that have utilized these approaches to examine family caregivers' talk during chronic health situations.

***Relational dialectics theory (RDT).*** Baxter and Montgomery (1996) proposed relational dialectics theory to assess the communicative and discursive tensions evident in personal relationships. According to Baxter (2004), when making decisions or establishing meaning, individuals give voice to these dialectical tensions that contain different and often competing discourses. Most research utilizing a dialectics approach examines talk of family caregivers for adult patients (Golish, & Powell, 2003; Golden, 2010; Kvigne & Kirkevold, 2003; Mirivel & Thrombe, 2010; Pawlowski, 2007), with only a few studies on parental caregivers' talk (e.g., Davis et al., 2013; Golish & Powell, 2003). Most recently, Davis et al. (2013) examined children's mental health team

meetings and the emergence of the strengths-deficit dialectic as case managers, parents, and children discussed children's health issues. When talking about a child, strengths-based language (i.e., acknowledging something positive to move forward in a positive direction) was often canceled out by deficit language (i.e., stating something negative that hinders moving forward in a positive direction), which hindered the ability to engage in hopeful discussions about the future. In a different study of parents in the neo-natal intensive care unit (NICU), Golish and Powell (2003) purported that parents experienced a joy-grief contradiction as they celebrated their premature baby's birth while simultaneously grieving the loss of a full-term pregnancy. Although not specifically focusing on communication, other researchers have started to elucidate parents' tensions with maintaining hope (Barrera et al., 2013; Jones, 2012), managing family equilibrium (Jones, 2012), and balancing care and medical decisions (Cadell, Kennedy, & Hemsworth, 2012; Jones, 2012).

***Uncertainty management theory (UMT).*** Uncertainty management theory goes beyond looking at the tensions within talk and disclosure, and considers the multiple and variable ways that individuals manage uncertainty (Brashers, 2001). The theorists (e.g., Babrow, 1992; Brashers, 2001) challenge original conceptualizations that uncertainty is always a negatively-valence concept that causes anxiety, inhibits one's ability to predict future events (i.e., uncertainty reduction theory; Berger & Calabrese, 1975), and results in behaviors that actively seek to reduce and minimize uncertainty (Bradac, 2001). Instead, within uncertainty management theory (Brashers, 2001), there is considerable variance across uncertainty experiences and meanings, and factors such as hope may influence individuals' communication behaviors to manage uncertainty. For example, information

avoidance as a way to maintain or increase uncertainty may be preferred if the health outcome is unfavorable (Babrow, 2001; Brashers, 2001; Mishel, 1988) or involves uncovering sensitive or difficult information (e.g., discovering the diagnosis of a terminal illness; O'Sullivan, 2008). As a way to maintain a desired level of uncertainty that facilitates better coping, individuals may rely on other people (e.g., health care providers, other family members) to help manage uncertainty or engage in certain information behaviors (e.g., information avoidance; Afifi & Matsungaga, 2007).

Similar to research on other communication-based theories, the corpus of UMT literature concentrates on adult patients and their family caregivers. This research has informed our understanding about uncertainty and information preferences across different illness trajectories, including: breast cancer (Babrow & Kline, 2000; Volkman & Silk, 2008), HIV/AIDS (Brashers, Haas, et al., 1999; Brashers, Neidig, & Haas, et al., 2000; Brashers et al., 2004), cancer (Clayton, Dudley, & Musters, 2008; Miller, 2014; Thompson & O'Hair, 2008), diabetes (Vevea & Miller, 2010), spinal cord injury (Parrott, Stuart, & Cairns, 2000), and being deaf (Karras & Rintamaki, 2012). To date, only one study has examined parental caregivers' uncertainty management after a positive newborn screening for cystic fibrosis. Dillard and Carson (2005) found that some parents sought information to reduce uncertainty about the disease and procedures associated with treatment, while other parents avoided information. Regardless of parents' information preferences, health care providers and family members collaboratively worked together to jointly manage uncertainty in a way that was desirable for parents.

***Communicated narrative sense-making (CNSM).*** Communicated narrative sense-making (Koenig Kellas et al., 2010; Koenig Kellas, 2005) is the process of

examining family stories and storytelling through a post-positivist lens to understand the functions within stories that lead to identity creation, socialization, and coping. By using this process to examine narratives, scholars seek to understand how narrative operates within the family in patterned ways that are associated with family health and well-being (Koenig Kellas & Kranstuber Hortsman, 2015). Communicated sense-making is considered to be the parent concept within the communicated narrative sense-making process. Here, individuals communicate in ways that make sense of their relationships, lived experiences, identities, and difficulties (Koenig Kellas & Kranstuber Hortsman, 2015). For example, family caregivers of adult patients receiving palliative oncological care have defined hope as both particularized (e.g., treatment, cure, miracles) and generalized (e.g., spirituality, family communication, false hope), and this hope is often considered to be paradoxical, such that hope is experienced and communicated both positively and negatively (Koenig Kellas, Castle, & Waters, 2014). Palliative care providers are recognized as crucial partners in helping family members talk about hope in a way that facilitates a healthy transition from restitution (i.e., individuals discuss departure from health to condition and back to health) to quest (i.e., body and self are profoundly transformed through the condition) narratives.

**Rationalization for a grounded theory study.** While each of the communication-based theories and frameworks mentioned above have furthered scholars understanding about parents' uncertainty, hope, and hopelessness, many of the studies utilizing these approaches have only tangentially (i.e., as opposed to directly) studied these concepts. *Relational dialectics theory* examines the *discursive tensions* surrounding a communicative interaction. *Uncertainty management theory* explains the variance

across how *uncertainty is managed*. *Communicated narrative sense-making* focuses on how *family narratives impacts individual identity*. Each theory concentrates on a particular component to the discursive interaction or narrative and does not specifically focus on talk about uncertainty, hope, and hopelessness, and how these concepts may be relationally situated to inform an understanding of parents' social constructions of uncertainty, hope, and hopelessness.

Although none of these theoretical frameworks will be directly applied, an awareness of the concepts within the frameworks, particularly as they relate to caregivers' uncertainty, hope, and hopelessness, is important in providing a landscape and knowledge base about communication. From this research, scholars know that uncertainty, hope, and hopelessness are related and communicatively constructed in a way that may lead to dialectical tensions (e.g., Davis, et al., 2013; Golish, & Powell, 2003; Golden, 2010; Kvigne & Kirkevold, 2003; Mirivel & Thrombe, 2010; Pawlowski, 2007; Verhaeghe, et al., 2007a, 2007b) or talked about paradoxically (Koenig Kellas et al., 2014). Individuals often manage uncertainty differently, and factors such as hope may serve as a primary goal influencing communication and coping behaviors (e.g., Babrow & Kline, 2000; Brashers, Haas, et al., 1999; Brashers, Neidig, & Haas, et al., 2000; Brashers et al., 2004; Volkman & Silk, 2008). Further, communication behaviors (e.g., conversations with others) may contribute to parents' social constructions of hope (Davis 2005; Davis et al., 2013).

I will extend current knowledge about parents' uncertainty, hope, and hopelessness by focusing on and theorizing about parents talk on these concepts as their chronically ill child receives medical or pharmacological treatment. I am interested in

studying the potential relationships among uncertainty, hope, and hopelessness and how communication behaviors may be a part of that process. Thus, a grounded theory is a well-suited approach for data collection and analysis because it affords researchers a set of flexible heuristic strategies to examine action processes in an attempt to “*theorize* how meanings, actions, and social structures are constructed” (Charmaz, 2006, p. 151). This approach aligns well with the two research questions (see Chapter 1).

### **Chapter 3: Methods**

When a child is living with a chronic condition, parents seek to make a valuable contribution to the care of their child (Shivanada Pai, Bhaduri, Goerge Jain, Kumar, & Sethi, 2008). The central aim of the dissertation was to understand parents' talk about uncertainty, hope, and hopelessness while their chronically ill child received ongoing medical or pharmacological treatment. Thirty-five parents of children diagnosed with complex chronic conditions were interviewed about their caregiving experiences, specifically focusing on their talk about uncertainty, hope, and hopelessness.

Studying parents' talk is one way to obtain more information about these dynamic concepts that are managed through and influenced by communication (Brashers, 2001, 2007; Brashers et al., 2004; Brashers, Neidig, Haas, et al., 2000; Davis et al., 2013; Duggleby et al., 2009; Duggleby et al., 2010; Olver & Elliott, 2002; Rodriguez-Hanley & Snyder, 2000; Thompson, 2011). Already, scholars know that information received (Roscigno et al., 2012; Verhaeghe et al., 2007a; 2007b), such as numerical information pertaining to a child's prognosis or treatment plans (e.g., time to progression, tumor reduction, maintenance of functional capacity; Thorne et al., 2006) has shown to affect parents' levels of uncertainty. Similarly, medical providers' choices of topics, choices of wording, and arrangements of conversations all contribute to parents' uncertainty and hope (Dillard & Carson, 2005; van Gurp, Hasselaar, van Leeuwen, Hoek, Vissers, & van Selm, 2013). Finally, negativity from family members affects parents' levels of hope during a child's treatment (Barrera et al., 2013). Given this research, a more thorough examination of parents' talk about uncertainty, hope, and hopelessness may inform scholars understanding about the potential relationships among these concepts and the

collaborative discursive processes influencing parents' constructions of uncertainty, hope, and hopelessness. This knowledge may be incorporated into family-based interventions that seek to improve the quality of life for parents and children affected by pediatric chronic conditions. The need for such interventions becomes particularly salient during a child's treatment period. During this time, parents may experience a host of uncertainties as the burden of care increases (Melnik et al., 2001), internal and external resources become exhausted (Lavee & May-Dan, 2003), and parents are expected to be the "bearer of hope" for the family (Verhaeghe et al., 2005).

### **Research Sample**

A total of 35 parents participated in the study, which included 28 mothers and 7 fathers. The average age of parents was 41.0 with ages ranging from 25 to 57. All parents self-reported White/Caucasian. In most instances, only one of the parents to the child was interviewed (N = 23); however, there were six pairs of parents (both mother and father) who were each interviewed separately. Most parents (N = 32) had only one child living with a complex chronic condition; however, there were three parents who had two children living with complex chronic conditions and, in those instances, the parent discussed information and stories relevant to both children. Other demographic information about the parents and their family composition is reported in Table 1.

Across the 35 parents interviewed, parents talked about 33 children who lived with complex chronic conditions that required ongoing medical or pharmacological treatment (see Table 1). A child's condition was considered complex because of its severity, comorbidity (i.e., presence of two or more chronic conditions), or rarity, as reported by the parent. The severity of a child's condition did not have to be permanent,

but must be presently apparent during the time of the parent's interview. In fact, 19 children were hospitalized for treatments or procedures at the time of the parent's interview. Children were diagnosed with a variety of different complex chronic conditions (see Table 1) and 10 children had co-morbid chronic health issues. The majority of children ( $N = 27$ ) had been living with their condition for a minimum of two years. Twenty-one of the children were male and 12 were female. Children ranged in ages, from 3 months to 17 years, with the average age being 8.6 ( $SD = 6.44$ ).

**Primary research location.** Parents were recruited in two different ways and from two different research locations. Twenty parents were recruited from the Ronald McDonald House Charities Eastern Wisconsin. This chapter is affiliated with The Ronald McDonald House.<sup>3</sup> Since 1974, the network of local Ronald McDonald House chapters annually provides housing and other services (e.g., laundry facilities, food, therapy programs, gifts) for more than seven million families with children in the hospital receiving medical treatment ([www.rmhc.org](http://www.rmhc.org)). Chapters are currently located in 58 countries and regions around the world.

In 1984, the Eastern Wisconsin chapter of the Ronald McDonald House Charities (RMHC) opened. Since then, more than 35,000 families have stayed at this House while a child receives medical care at one of the local hospitals ([www.rmhcmilwaukee.org](http://www.rmhcmilwaukee.org)). In 2013 alone, more than 1,000 families were served at this location. Families who stay at the House receive private rooms, family meals, access to therapy programs (e.g., art, dog, music), and private spaces around the House for relaxation and reflection (e.g., chapel, Secret Garden). As long as an open room is available, any family is eligible to stay at the

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<sup>3</sup> A non-profit 501(c)(3) corporation funded by individual and corporate donors and supported by thousands of volunteers.

House, so long as they do not reside within the immediate county and have a child receiving medical treatment at one of the local hospitals. A suggested donation of \$10/night is encouraged, but no family has ever been turned away due to an inability to pay this amount. In fact, many families often do not have the financial means to afford their stay, but are allowed to reside at the House for the entire duration of their child's hospitalization. According to Ann Petrie, RMHC President and CEO, last year alone, over 800 families were turned away due to a lack of available rooms (Wahlberg, 2013). As a result, in Fall 2014 the House completed a \$10 million expansion project to add 32 guest rooms, a new entrance and reception area, two-level parking structure, fitness center, music room, study rooms, and family kitchens to accommodate families as well as the family meal program.

Parents staying at the Ronald McDonald House were recruited through flyers posted around the House informing them about the research project. The flyer contained a description of the study (i.e., one-on-one, face-to-face interviews), the purpose (i.e., to learn more about parents' experiences caregiving for children with chronic conditions), and inclusion criteria (i.e., parents over the age of 18 with a child who has a diagnosed medical and/or psychological condition lasting for a minimum of six months and currently receiving medical treatment).

Any parent or parental surrogate with a child receiving ongoing medical or pharmacological treatment for a chronic condition was eligible to participate. However, in order to adhere to the focus of the study (i.e., parental caregivers), other family relationships (e.g., aunt/uncle, grandparent, sibling) were excluded from participating unless that person was considered to be the parental surrogate. In the case of dual-parent

households, both parents were eligible to participate; however, each parent was interviewed separately in order to prevent individual experiences from being biased or confounded by the presence of the other parent. Finally, in order to adhere to the focus on parental caregiving during a child's treatment period, the child must have been diagnosed for a minimum of six months and currently be receiving medical or pharmacological treatment at the time of the parent's interview. The six-month post-diagnosis time frame was selected to ensure that parents were past the diagnostic stage and in the treatment period, a time that is ripe with uncertainty (Melnyk et al., 2001) and remains relatively understudied (da Silva et al., 2010).

**Secondary research location.** Fifteen parents were recruited through the local and regional community. These parents were recruited by promotions on local online listservs (e.g., Southeastern Wisconsin chapter of Juvenile Diabetes), members within my social network, and social networking websites (i.e., Facebook). Parents were also recruited through chain sampling by parents who already completed the interview. Chain sampling is an effective way to target participants with key selective criteria (Ritchie, Lewis, & Elam, 2003). Eligibility and inclusion criteria remained the same for these parents. In accordance with principles from grounded theory, the sample size was not predetermined; rather, recruitment and the final sample size ( $N = 35$ ) were determined once theoretical saturation was complete (i.e., categories supported with enough data to obtain theoretical sufficiency; Charmaz, 2006; Cohen, Manion, & Morrison, 2007; Lincoln & Guba, 1985).

### **Data Collection**

Data collection took place over a 10-month period (June 2014 to March 2015). A

detailed account of the procedure and data collection sources is further enumerated.

**Procedure.** Sources of data included: (1) initial screening, (2) semi-structured interview, and (3) a brief demographic questionnaire. All portions of the data collection process were audio-recorded and occurred face-to-face in a private location (e.g., private office space at the RMHC, private room at person's house, or other preferred location). Prior to the interview, initial screening was conducted to ensure that parents were eligible to participate. As subsequent parents were theoretically sampled, initial screening also ensured that parents' experiences could refine and strengthen the emerging categories. Once eligibility was confirmed, the interview began and was followed by a brief demographic questionnaire completed independently by the parent.

Semi-structured, in-depth interviews were selected as the primary method for data collection because this method allows for obtaining rich, thick descriptions that detail individual experiences. Further, interviews allow researchers to: (a) understand communicative phenomena that cannot be observed directly or experimentally (e.g., thoughts and feelings), (b) examine how participants use language in their natural environment, and (c) illuminate interviewees' communicative style to be transparently represented within the data (Baxter & Babbie, 2004; Donovan et al., 2014). Interviews also allow the researcher to probe for more information, which is critical for assessing retrospective communication behaviors across time and situations (Metts & Lamb, 2006).

Although not a prominent approach within qualitative methodology, a brief demographic questionnaire was administered after the interview was complete. Demographic questionnaires may be used to capture information about the context in which participants are situated (Ritchie, 2003). The questionnaire included brief open and

closed-ended questions that asked about background and contextual information regarding the parent (e.g., parents' relationship status, family composition, parents' highest completed education), as well as specific information about their child living with the chronic condition (e.g., name and duration of child's diagnosis, type of medical or pharmacological treatment, number of hospital visits within the past six months, the child's prognosis). These questions were necessary because the interview focused on the open-ended questions regarding parents' experiences and communication behaviors, and this format did not allow for the ability to capture these brief factual questions in an abbreviated amount of time. Subsequently, the questionnaire provided a shorter and condensed format to seek parents' responses about these pertinent factual details.

The entire data collection process was piloted with three parents who had a child receiving treatment for a chronic condition. Piloting the data collection procedures is a critical step in the research process because it provides an initial assessment of the scope of the study and whether participants are able to give a full and coherent account to the central issues being examined (Arthur & Nazroo, 2003). Sampling for the pilot interviews was purposive; the three parents who were interviewed met the eligibility criteria. The first two parents (mother and father) had a 17 year-old daughter with osteosarcoma who was undergoing chemotherapy and radiation treatment. The third parent was a mother of a 16 year-old son with intractable epilepsy. The son was preparing for a vagus nerve stimulation surgery and had previously received several medical and pharmacological treatments to manage his condition. After participating in the interviews and questionnaire, these parents commented on the verbiage used in the interview and questionnaire and offered feedback on the entire data collection process. None of the

parents had any grave concerns or substantial feedback, so the interview guide and demographic questionnaire remained the same for the subsequent interviews. Because the data collection process was not substantially altered, these pilot interviews were also included in the overall research findings (e.g., Arthur & Nazroo, 2003).

***Initial screening.*** Prior to conducting the interviews, parents were asked whether they were the parent and/or legal guardian of their child who had a diagnosed chronic medical or psychological health condition that persisted for a minimum of six months and was currently receiving medical or pharmacological treatment. As more focused interviews were conducted, parents were also asked about the complexity of their child's condition, so as to fit within the confines of the study and model. Non-English speaking parents were excluded from the study because of the communication barrier. Upon indicating that an individual met these eligibility requirements, parents provided informed consent.

***Semi-structured interviews.*** The interview began after parents signed the informed consent. The majority of the interviews lasted for 60 to 90 minutes and were conducted in a private location of the parent's choosing, either a private meeting room at the Ronald McDonald House or at the participant's home. A semi-structured interview guide was utilized that included: (a) general questions about parents' caregiving experiences during the treatment period of their child's chronic condition; (b) specific instances pertaining to their experiences with uncertainty, hope, and hopelessness; and (c) recollection of significant conversations that occurred and/or information received during these different moments. Appendix A contains the semi-structured Interview Guide. As the interview evolved, a combination of content mapping (i.e., questions used to open up

the research territory and identify the dimensions that are relevant to the participant) and content mining (i.e., questions used to explore the detail, meaning, and generate an in-depth understanding; Leegard, Keegan, & Ward, 2003) questions allowed me to probe for additional information while still providing parents the space to generate their own narratives (McAdams, 1993). Throughout the interview, a research assistant and myself recorded field notes to: (a) capture moments outside of what was audibly recorded, (b) record personal thoughts and feelings about the interview, (c) present ideas and questions for inclusion in subsequent interviews, and (d) highlight thoughts that may be developed into memos during the analytical stages (Charmaz, 2006).

***Demographic questionnaire.*** After the interview, parents completed a brief questionnaire that included questions about demographic information (e.g., parents' age, race/ethnicity, relationship status, highest completed education, total number of children) and questions pertaining to their child's health condition and treatment (e.g., diagnosis, prognosis, previous hospitalizations, and current treatment) in order to provide a health profile of the child. Appendix B contains the demographic questionnaire.

### **Data Analysis and Synthesis**

Data collection and analysis was completed with the help of two undergraduate research assistants. Both research assistants had some prior experience with qualitative methods (i.e., interviewing, transcription, coding, constant comparative analysis). I provided additional training to the research assistants on the protocol for transcription and analysis by having them read chapters about grounded theory methods from Charmaz (2006) and regularly meeting with them to discuss these processes. The two research assistants and one graduate student transcribed, verbatim, all of the audio-recorded

interviews, and I verified the accuracy of the transcripts. To protect identities, all audio files and transcripts were number coded and assigned a pseudonym. All other identifying information (e.g., parent's and child's name, name of hospital where child was receiving medical treatment) was removed from the transcript. Consistent with grounded theory and constant comparative methodology, the processes of data collection and analysis occurred concurrently (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Strauss & Corbin, 1990).

Initially, 12 parents were interviewed about their caregiving experiences, with respect to uncertainty, hope, and hopelessness (see Appendix A). The sampling for these parents was purposive in order to interview parents who could address the initial research questions within the confines of the study. After analyzing data from the initial 12 interviews for content and developing preliminary codes and themes from the inductive analyses, 23 focused interviews were completed with additional parents. For example, when exploring the dimensions of the theoretical category, *comparing self to others*, I gathered more data on how parents formed comparisons between themselves and others, where parents sought information, how parents used this information to inform their own understanding of their child's condition, and how their interactions with other people affected their assessments of normalcy. Theoretical sampling was used recruit the remaining parents whose experiences deemed tenable in elaborating and refining the concepts within the emerging grounded theory. This type of sampling facilitates conceptual and theoretical development and is considered to be a major strength of grounded theory (Charmaz, 2006).

Both of the undergraduate research assistants and I independently analyzed all

transcripts and field notes and then convened at weekly meetings to test and refine our ideas about the interrelationships among emerging codes and categories. The analysis of the contextualized grounded theory started with three sensitizing concepts (i.e., hope, hopelessness, uncertainty; Charmaz, 2006) that were used to examine the first set of parents' transcripts for statements about uncertainty, hope, and hopelessness. As categories pertaining to these concepts developed during the individual and group constant comparative process (Corbin & Strauss, 2008; Glaser, 1978; Glaser & Strauss, 1967; Lincoln & Guba, 1985), questions were added to the interview guide to test and probe nascent themes against each other and alongside the initial sensitizing concepts (Bowen, 2006). For example, the emerging category *constructing the "new normal"* evolved from the data as many parents talked about the ongoing life changes that occurred since their child's diagnosis. Many parents used the word "normal" to describe their current life in comparison to their previous life or others' lives. As we identified this category, we asked parents in the focused interviews to talk about their life changes since their child's diagnosis, what "normal" meant to them, and how their family now functions. Thus, as categories and themes emerged within the grounded theory these topics were explored in more detail during subsequent interviews with other parents.

Coder agreement was established through a series of weekly discussions over the course of eight months, per grounded theory principles (e.g., Charmaz, 2006; Strauss & Corbin, 1990). For example, two of the three researchers recognized hope and hopelessness as related concepts that were situated within parents' chronic uncertainties about their child's health condition. Although hope and hopelessness fluctuated based on different external factors (e.g., information seeking, conversations with others, social

support), parents' uncertainties were described as chronic. Initially, one of the research assistants did not recognize uncertainty as the concept framing the entire model. To explain their thought process for having uncertainty encompass the entire model, the two researchers provided evidence from the transcripts to support their conclusions. During this conversation, the other research assistant agreed with having parents' talk about hope and hopelessness situated within the concept, *acknowledging chronic uncertainty*. When other differences surfaced about how the model was constructed, we discussed our reasoning with the group and provided evidence within parents' transcripts to justify conclusions. Verification that individual interpretations of the themes and connections were clearly grounded within the data was based upon entire group consensus. New propositions within the grounded theory were not deemed tenable until they were tested via additional interviews and reached group consensus. Theoretical sampling provided an intentional process to collect pertinent data that informed and refined the categories and themes within the emerging grounded theory (Charmaz, 2003, 2006; Corbin & Strauss, 2008; Ritchie et al., 2003).

Consistent with grounded theory, independent and group coding involved three steps: open, axial, and selective. During open coding, transcripts were independently analyzed, line-by-line, to identify properties and examine the dimensionality of each subcategory (Strauss & Corbin, 1990), specifically focusing on parents' talk about uncertainty, hope, and hopelessness. We used *invivo* coding, a process of using a word or short phrase taken directly from the data (Saldaña, 2013). This coding technique ensured that concepts remained as close as possible to parents' own words and captured key elements of what was being said. We also used gerunds to capture the actions described

by parents (e.g., avoiding, managing, talking, seeking; Charmaz, 2006; Glaser & Strauss, 1967). Although uncertainty, hope, and hopelessness served as sensitizing concepts, in this stage of coding, we remained open to the possibility of other concepts emerging within the data. Some of the categories included: *focusing on the present*, *waiting*, *receiving social support*, *seeking information*, *facing obstacles*, *maintaining flexibility*, *feeling alone or burdened*, *constructing normalcy*, *making comparisons*, and *acknowledging chronic uncertainty*. After making a list, narrative memos were written for the common preliminary categories from the open coding process (Strauss & Corbin, 1990). For example, *waiting* was a category that emerged during this process. *Waiting* derived from the chronic uncertainty that parents experienced and was described as being a response to parents' living in chronic uncertainty. For instance, parents mentioned having to wait to receive the official diagnosis, determine the appropriate course of treatment, and assess the effectiveness of ongoing medical or pharmacological treatments. During this time, parents often talked about why they and other family members were waiting (i.e., test results, a child's reactions to new medical treatments). When writing the memo about *waiting*, examples of parents talk related to this concept were also included in the memo.

During axial coding we organized and collapsed the data into categories and subcategories to present an overall view of the findings (Strauss & Corbin, 1990) into "a coherent whole" (Charmaz, 2006, p. 60). During this stage, further examination of the transcripts helped us identify theoretical connections among the emerging categories. Categories that overlapped were collapsed into a single group and the attributes of each category were thoroughly described. A detailed explanation of the categories was

important because a robust theory is dependent on the detail and description used to explain the categories and the relationships across categories (Corbin & Strauss, 2008). The axial coding process was iterative and involved multiple rounds of assessing the relationships across categories and postulating about the theoretical story behind the data. Some of the categories that emerged from this process included: *acknowledging chronic uncertainty*, *maintaining hope*, *feeling hopeless*, *forming comparisons*, and *constructing the “new normal.”* For example, the theme of *acknowledging chronic uncertainty* became the concept framing the entire model. Parents would discuss how everything about their child’s treatment remained unknown and provided a list of uncertainties that prevailed. In response to living in chronic uncertainty, parents reported enacting three different behaviors—*waiting endlessly*, *feeling heightened emotions*, and *questioning the future*.

In the final stage of selective coding we organized the categories around the core category of *comparing self to others* (see Chapter 4). This core category inductively emerged through the constant comparative process of analyzing parents’ talk about uncertainty, hope, and hopelessness. Table 2 includes a list of the different categories, subcategories, and themes as demarcated within the model. *Comparing self to others* was conceptualized as a communicative and psychological process that encompassed seeking information and assigning meaning to differences. This theoretical category connected the other categories to one another. Once the model was created, the entire model was tested against additional transcripts until theoretical saturation was achieved.

Theoretical memos were maintained throughout the conceptual development and analysis (Strauss & Corbin, 1990). Memo-writing provided documentation and reflection

of coding processes and code choices; how the process of inquiry was taking shape; and the emergent patterns of categories and subcategories (Saldaña, 2013). Once the model was established, findings were presented in the form of a narrative (Saldaña, 2013) that included a description of the model, as well as direct quotes from parents' transcripts to serve as explanatory evidence that supports the theoretical analysis (Charmaz, 2006).

These findings were then tied to the existing literature to strengthen the explanation of the emerging theory (see Chapter 5), and the new findings were situated where gaps exist in the literature to build credibility of their existence.

### **Other Methodological Considerations**

**Researcher positionality and reflexivity.** Researcher positionality acknowledges the position of the researcher as a co-constructor of the research process and the data that is collected (Berger, 2015; Wolcott, 2009). According to grounded theorist, Kathy Charmaz (2006), "knowledge is not neutral, nor are we separate from its production or the world." (p. 185). Thus, researcher positionality is of paramount importance to grounded theory methods because of its influence on the concurrent processes of data collection and analysis and how different researcher characteristics impact these findings (Creswell, 2007). My positionality with respect to this project directly influenced the topic and focus of my dissertation. For three years, I have been serving as a House volunteer at RMHC, the primary site for recruitment. In this role, I have helped with administrative tasks in the front office (e.g., answering the phone, filing papers) and around the house (e.g., making beds, cleaning rooms, vacuuming the house). I have had several opportunities to meet some of the families who have stayed at the House, hear their personal stories pertaining to their child's condition and treatment, and learn about

how they are making family adaptations during this stressful and uncertain period. In addition, I have conducted participant observation research of the House's art therapy program for over a year. For that research project, I examined how the families used art as a medium to communicate about coping with children's acute or chronic conditions. My involvement with this research project in conjunction with my monthly volunteer experiences prompted my interest in studying family caregivers of children with chronic conditions. As I refined my dissertation focus, I decided to concentrate on parental caregivers given their significant role in managing a child's health condition (Goldsmith et al., 2011).

My positionality significantly changed as I began the concurrent processes of data collection and analysis. Of significant importance, I was pregnant with my first child as I wrote the dissertation proposal. Further, I was in the second and third trimester during the first four months of data collection and analysis. My pregnancy was visibly apparent to the parents that I interviewed. In fact, most of the parents asked me questions that signified their acknowledgement of my pregnancy: "When are you due?" "Is this your first child?" and "Do you know what you are having?" Further, many parents would reference my positionality as an expectant mother to what they were disclosing in the interview: "you will know what I am talking about soon" and "when you have your child, you will just know and learn what they need." These comments demonstrated the salient role that my pregnancy had in the interview process, which influenced the amount and type of information that parents disclosed with me. Factors such as being pregnant are likely to shape the nature of the researcher-researched relationship and participants are often more willing to share their experiences with a researcher whom they perceive as

sympathetic to their situation (Berger, 2015).

After each interview, I wrote memos to reflexively examine my positionality and actively acknowledge how this position affected the research process (Berger, 2015; Bradbury-Jones, 2007; Stronach, Garratt, Pearce, & Piper, 2007). I also wrote about my own feelings and emotions regarding the stories that parents discussed, and how this information impacted my own identity that included my own uncertainties about my future child and upcoming labor and delivery. Through the data collection process, I realized that the parents who I interviewed were influencing my own identity as an expectant mother. Although I tried to distance myself from them as a way to manage my own uncertainties about whether I would become a parent to a chronically ill child, I found myself becoming changed and more open to the possibility of this happening. After all, the interviews with parents were not something that I could intentionally avoid if I wanted to complete my dissertation.

Initially, allowing for a more open perspective about my child's health was emotionally distressing and challenging as I had not originally anticipated that something could happen during labor, delivery, or shortly thereafter. Like many expectant mothers, I was naïve to the possibility of anything “wrong” happening to my future child or myself during labor or delivery. Further, I had enough uncertainties about neither knowing the sex of my child nor completing any genetic testing beforehand. Nonetheless, as the concurrent processes of data collection and analysis evolved, I began to realize and accept that a healthy child was not a guarantee. Comments from mothers like “I had a normal pregnancy and didn't know anything was wrong until post-delivery” forced me to consider the potential of having a child with a chronic health condition. These statements

added to my fear of the unknown. In an attempt to manage my uncertainties and fears, I found myself developing a more open and vulnerable perspective about my own labor and delivery and would often tell my husband and myself that a healthy child was not a guarantee:

No one is given a free pass when it comes to health. Some people may have good health until the end of their life, while other people are sick starting in utero and it is recognized before the child is born or at birth. Knowing that illness is something that affects us all at some point in our life, I find myself starting to embrace the uncertainty and unknowns regarding my own child's health. He or she may not be healthy, and if that is the case then my husband and I will manage this situation when it comes. The parents that I have met have been an inspiration amidst such trying and difficult circumstances. I am hopeful that I would be able to rise to the occasion with the same strength and positive attitude as them. (Personal Memo after an interview, September 6, 2014).

In some ways, these interviews forced me to prepare for the worst possible scenario that could happen during labor and delivery – receiving a negative health diagnosis, or even the still born death of my child.

Since data collection and analysis has ended, my identity continues to evolve and I have transitioned from being an expectant mother with many uncertainties about my future child to a mother with a “mostly” healthy son. Although some of the original uncertainties about my son's health have eased now that he is born, I am still cognizant that something could happen to my son's health in the future. Just because I am not currently a mother to a son with a chronic health condition does not mean that I may never assume this identity.

My worldview and background has changed by interviewing these parents and becoming a mother. Together, these experiences have influenced the way that I now construct the world and make meaning of it, and as such, these factors have likely shaped the findings and conclusions from this study (Kacen & Chaitan, 2006). For example,

when mothers would talk about “doing anything for their child,” these statements now have a tangible meaning to me. I am now able to personally relate to these statements and have similar sentiments regarding my own son’s well-being and health. Further, as I analyzed the data, the core category that emerged was *comparing self to others*. Just as the parents that I interviewed would form comparisons with other parents or families, I too found myself making comparisons to the parents that I interviewed. As I listened to and analyzed parents’ stories about caring for their child and his or her condition, and the uncertainty, hope, and hopelessness that they experienced, I would compare what they would say to my own feelings of uncertainty, hope, and hopelessness regarding my son and his health.

A recent personal example where I engaged in the process of *comparing self to others* occurred when my son was diagnosed with chicken pox. Although chicken pox is not a chronic health condition, his condition was considered severe for an almost two-week period, given his young age at the time of being symptomatic (i.e., 4.5 months). During this time, I reflected on how my own experiences as a mother with a sick son resembled some of the experiences from the parents that I interviewed. My husband and I were forming comparisons to other children and previous points in my son’s health to gauge the severity of his case and his reactions to being sick. Further, these comparisons were formed by seeking information online and by talking with other parents and medical providers. During this time, we did maintain hope by reframing towards positivity and relying on our Christian beliefs, but at times we also felt hopeless, particularly when he had a low-grade fever for several days that required extensive monitoring and increased care. In order to provide the best care for my son, my husband and I had to restructure our

“new normal” as we were now waking up several times throughout the night to take his temperature, administer medications three times daily, force him to eat, and bathe him twice a day. This entire time was rife with uncertainty until his condition subsided and we received the guarantee from his physician that everything was now fine. This example conveys that just as the parents I interviewed constructed the “new normal” in an attempt to adapt to perpetually changing circumstances, I was constructing my “new normal” while managing his condition. In addition, my own transition from being a married woman to a mother of a son during this dissertation process has made me realize that significant life-changing transitions, such as having children or those children becoming sick, often require parents to construct their “new normal” as their life becomes transformed. When reflecting on the grounded theory process Charmaz (2006) states, “when you bring passion, curiosity, openness, and care to your work, novel experiences will ensue and your ideas will emerge” (p. 185). My journey throughout the grounded theory process of this dissertation demonstrates my openness to the research experience and the resultant transformation that occurred from it.

**Establishing trustworthiness in the research process.** The trustworthiness standard in naturalistic research is in contrast to the conventional, positivistic criteria of internal and external validity, reliability, and objectivity (Charmaz, 2006; Denzin & Lincoln, 2003; Lincoln & Guba, 1985; Riessman, 2008). Therefore, Charmaz’s (2006) criteria were used for the assessment of scientific rigor. Accordingly, *credibility* (i.e., data is sufficient to merit the claims with strong logical inks between the gathered data and the analysis; Charmaz, 2006) was first established by completing a thorough and focused literature review that strengthened the argument for studying the phenomenon. This

literature review was included as part of the dissertation proposal and has since been edited and revised as the dissertation has evolved. Credibility was also maintained by collecting rich data through multiple methods of data collection (i.e., interviews and field notes from the interviews) and through adherence to grounded theory processes and procedures (i.e., Charmaz, 2006). Transcribing interviews and field notes and maintaining a detailed description of the research process created an audit trail. The audit trail of written memos demonstrated the dependability of the results and ensured that the results were reflective of the data and not representative of subjective biases (Guba & Lincoln, 1985). These detailed memos were shared with the other research assistants and my advisor throughout the data analysis process. Credibility was also assured through member-checking (i.e., sharing the written results and grounded theory with some of the parents who were interviewed; Charmaz, 2006) the model with some of the parents who participated in the interviews. By transcribing interviews verbatim, using *invivo* coding (Saldaña, 2013), and including parents' authentic quotes to describe the processes and subprocesses within the model, *originality* (i.e., proffering an analysis that provides a new conceptual rendering of the data; Charmaz, 2006) was maintained. In addition, a final literature search was integrated into the findings and is presented in the discussion chapter (see chapter 5). Finally, as advanced by Charmaz (2006), reviewing and revising the findings with additional parents who participated in subsequent focused interviews ensured *resonance* (i.e., portraying the fullness of the studied phenomenon that draws links to larger collectives and individual lives) and *usefulness* (i.e., how the research contributes to scientific knowledge and improves individual's lives).

A final goal of the study was to provide transferable findings. Transferability is a

term coined by Lincoln and Guba (1985) and is synonymous with the quantitative term generalizability (i.e., external validity). Rich, detailed descriptions about participants and their experiences provided a basis for the findings to be applied in a broader context, such as other parents facing similar experiences with a child who has a chronic condition. In addition, transferability was achieved by systematically comparing observations within and across parents' interviews to produce a plausible and coherent explanation of parents' talk that contributed to their social constructions of uncertainty, hope, and hopelessness (i.e., Charmaz, 2006; Thomas & Magilvy, 2011).

**Ethical considerations and institutional review board approval.** All research raises ethical considerations, so ensuring the ethical protection of participants is a vital concern. In qualitative research, the in-depth, unstructured format may present unanticipated challenges (e.g., participants not feeling comfortable or provide answers that lack descriptive detail). Therefore, the ethical issues in the present study were thoroughly examined and approved by the University's Institutional Review Board. Further, during data collection and analysis, several protocols were followed to ensure the protection and rights of participants. Parents were informed about the purpose of the study preemptively, and participation was voluntary. Written informed consent was obtained from all parents prior to the interview. Participants' and their families' identity remained confidential throughout the data collection and analysis processes. Numbers and pseudonyms were assigned to all transcripts, and all identifying information (e.g., names of cities), was notated in brackets to protect the parents' privacy. After interviews were complete, member checks with some of the participants allowed parents to confirm that identities were adequately disguised (Riessman, 2008). Finally, precautionary

measures were taken to secure all research-related files and transcripts. All data was secured in a locked office with a password-protected computer. Nobody other than the research assistants, doctoral advisor, and myself had access to the data.

## Chapter 4: Results

In this chapter, I describe a model (Figure 1) pertaining to how 35 parental caregivers talked about uncertainty, hope, and hopelessness amidst caregiving for a chronically ill child with a complex condition that required ongoing medical or pharmacological treatment. The findings are organized into a framework that describes and explains how parents' talk about these concepts centers around the core category of *comparing self to others*. Figure 1 provides a visual representation of the model and Table 2 denotes the different categories and themes within the model. A description of the model, including an assessment of the relationships among the core category and other categories and themes are first enumerated. I then describe each of the categories and themes within the model and incorporate parents' quotations within the descriptions.

### Summary of the Theoretical Model

Figure 1 contains a diagram of the emerging theoretical model that describes a process about how parents experience uncertainty, hope, and hopelessness amidst treating a child's complex chronic condition. This process was understood by analyzing parents' talk from interviews that included questions about their uncertainty, hope, and hopelessness, while their children received treatment for his or her complex chronic condition. Parents acknowledged chronic uncertainty as the framework within which the rest of their experiences resided; thus, this category is the exterior of the model and provides a context within which the rest of the findings are interpreted. As parents talked about uncertainty, this talk was characterized by three themes: waiting endlessly, questioning the future, and feeling heightened emotions. These attributes were used to describe what parents were experiencing with respect to uncertainty, and also

characterized the content of conversations that parents described having with other people (e.g., other parents, friends, family members, medical professionals) about their uncertainties.

Situated within parents' talk about uncertainty was language about normalcy, differences, and change. Thus, *constructing the "new normal"* emerged as a category within uncertainty that included talk about striving for normalcy and making changes. A reciprocal relationship existed between the categories of *acknowledging chronic uncertainty* and *constructing the "new normal,"* such that talk about uncertainty influenced parents' "new normal" and vice versa. At the pinnacle of parents' talk about *constructing the "new normal"* emerged the central category *comparing self to others*—a recursive communicative and psychological process that involved seeking information and assigning meaning to differences. Within this social comparison process, parents described how comparisons influenced their assessments of the "new normal," as well as the use of comparisons in navigating the inherent tensions between maintaining hope and feeling hopeless. Parents' reported continuously oscillating between hope and hopelessness throughout their child's treatment period. Oscillation was generated back and forth based on parents' comparisons and how their assessments from outside information or sources (e.g., the child patient, medical providers, family members) paired with different factors that either resulted in parents maintaining hope or feeling hopeless. Parents discussed *maintaining hope* when the social comparisons assisted them with finding a supportive community, relying on religious and spiritual beliefs, and reframing towards positivity. In contrast, parents described *feeling hopeless* when the comparisons were coupled with experiencing overwhelming obstacles, dreading the "what-ifs" and

suffering from anticipatory grief.

In the following sections of this chapter, the central category—*comparing self to others*—will be further explained, followed by a discussion of the other categories and themes within the model.

### **Parents' Core Social Process: Comparing Self to Others**

Parents qualified *comparing self to others* as an iterative communicative and psychological process, in which principles from this core category transcended across all of the categories (i.e., acknowledging chronic uncertainty, constructing the “new normal,” maintaining hope, and feeling hopeless) within the model. This core category influenced how parents talked about their experiences with uncertainty, hope, and hopelessness, informed parents’ constructions of normalcy, and proffered an understanding about how tensions between parents’ hope and hopelessness were navigated in a way that often resulted in parents maintaining hope amidst uncertainty. In fact, one mother with two children diagnosed with two different complex chronic conditions highlighted the pervasive nature of comparisons in how she experienced uncertainty, hope, and hopelessness, and shared that she frequently had conversations with her husband and therapist about her feelings. During the interview, she recounted a recent conversation:

A lot of what I do I find myself doing is just networking... What information do you have and what information can I share with you. I am always trying to be a couple years ahead of my children. (daughter has epilepsy and son has mental illness)

To some degree, all of the parents also recounted similar processes of navigating uncertainty, hope, and hopelessness. Parents described going online, talking to other people, and making decisions for their children’s treatments based upon the information

gathered and the comparisons formed between others and them. Thus, seeking information and assigning meaning to differences were the two themes characterizing this process.

**Seeking information.** Seeking information was described a central part of being a parental caregiver and initiated the *comparing self to others* process. Immediately upon receiving a child's chronic diagnosis, parents felt the need to become experts on their child's condition and treatment, and subsequently started seeking information online and through other sources (i.e., friends, family). A significant resource mentioned was other parents with children who had similar health conditions. These other parents provided them with credible information about how to manage care and important considerations regarding medical treatments. For example, one mother whose daughter had cancer talked about how she recently used information from other parents in the community and on Facebook to provide assistance with making decisions about her daughter's chemotherapy treatments. She regarded her information-seeking role as significant and detailed how it gave her a sense of control that was mostly lost because of all of the uncertainties surrounding her daughter's condition:

One of the biggest challenges is that I can't do anything but love her. That's all I can do. I can't do the chemo for her, or I can't—there's not a cure that I can give her that is one hundred percent. All I can do is research, talk to other parents to make the best options for her. (daughter has cancer)

Parents regarded the relationships with these other parents as crucial because they allowed them to form equitable comparisons between their child and other children living with similar conditions. Thus, parents' reliance upon one another served as a type of barometer for gathering important information and making assessments. Assessments about what was "normal" for that condition became particularly important for parents

when new health problems surfaced or when a child's condition was considered rare. For instance, one mother whose son had congenital hyperinsulinism, a rare condition in which hypoglycemia is caused by excessive insulin secretion, talked about relying on the different parents within her Facebook group:

A comparison to normal kids or well kids is hard. They don't have to go through all this stuff. They don't have to give their kids medicine and live in fear of getting the stomach flu. So, it is nice to be able to compare to other families who are going through the same thing... One of the side effects of [the name of drug that her son is taking] is hair growth. And I felt like if I asked on my general mom's group, "okay, should I shave my child?" I would get this really negative response like, "no don't do that." I kind of brought it up on the hyperinsulinism group and people were like, "no we do."

Almost all of the parents interviewed belonged to at least one Facebook group specific to their child's condition. Within these groups, parents asked questions, provided responses to other parents' questions, and posted pictures and updates of their children. Thus, Facebook, as well as other online websites (i.e., Caring Bridge sites, National Cancer Institute), provided parents with credible and timely information in which they were able to form sufficient comparisons.

Parents also mentioned seeking information from other family members (e.g., spouse, adult parent), friends, and medical professionals. These sources provided information that helped parents make treatment decisions and manage daily living. For example, one mother mentioned several people within her support network that she valued as important sources for helping her glean useful information:

I talk to my friends who work in the school districts, you know, work with special needs. And then, with the Adaptive Sports Association you talk with other parents and you find out how things work. When we moved out here I actually, I interviewed ten schools. I went to ten different schools and checked out how they worked, and you know, what their floors were like, where his classes would be, how much movement he'd have to do during a day, how they felt about [his condition], how they treated it? (son has cerebral palsy)

By seeking information from these other people she was able to make decisions that improved her son's quality of life.

Many of the parents described seeking information from medical professionals to learn more about their child's condition or treatment, such as one mother's attempt to learn more about her son's condition when problems surfaced:

The vast majority of times we have gone in there for something that we are panicking about and [the doctors say] "Take a deep breath. It's okay." But you don't know until you get there and have an actual doctor look and see.... One time he had a vascular anomaly in the bottom of his eye. He woke up one morning and his eye was swollen and he was like, "what's going on?" Immediately [the doctors] saw him. But, they can't tell you over the phone because they can't look at it and see. (son has venus malformations)

In addition to physicians, other medical professionals (i.e., nurses, social workers) were also mentioned as important sources for seeking accurate and credible information.

Unfortunately, medical professionals were not always able to provide parents with the clarity and answers they desired when seeking information. For example, one father to a 17-year-old son with epilepsy (i.e., 3-10 seizures every 3-10 days which totals to over 1,000 seizures in his lifetime) expressed the challenges that he and his family faced as they attempted to best manage his son's condition at home, while also preparing for his upcoming vagus nerve stimulator surgery:

He has seen over 20 specialists, tried over 30 anti-epileptic drugs (AED), over 15 AED combinations, and 10 new AEDs. Due to brain surgery, AED, and seizures he has severe cognitive delays, speech concerns and AED side effects. We still do not have complete seizure control. No matter what we seem to do, we can't seem to find a pattern and then we found out there is no pattern. And it's just trial and error, just constant trial and error.

Parents who were in a similar situation expressed frustrations with not having the information they desired. These parents often reported turning to online sources to seek

information about alternative medicines and food diets in an attempt to treat recurrent symptoms.

Finally, in an attempt to provide the best care possible for their child, most parents discussed traveling across the country several times to get second opinions from medical experts and specialists and enroll in clinical trials or specialized in-patient treatment programs. Parents often sought out these professionals on their own. In other instances, parents were prompted by medical professionals to seek more advanced help. For example, one mother was prompted by her son's primary care physician at home to find a medical specialist to treat his severe aplastic anemia, a rare condition where bone marrow fails to make enough blood cells for the body. The survival rate of severe aplastic anemia in the state in which her family resided was zero percent, which led her to seek outside sources for help:

[The doctor] said, "Mrs. Drew if you have an expert for us to interface with, we'd appreciate that. You know, we don't mind interfacing with someone, another doctor." That kind of lit a fire under me and I thought I need somebody who knows what to do. (son has severe aplastic anemia)

During these moments parents turned to national organizations and association websites to find these people and glean important information about treatments and specialists.

**Assigning meaning to differences.** In addition to seeking information face-to-face and online, parents reported assigning meaning to differences as they interacted with other "healthy" children and family members. One mother described the differences she noted between her chronically ill son and her "healthy" nieces and nephews when they played together:

I have two brothers who also had babies within like a couple of weeks of him, so we're with his cousins all the time. And when I see him with them it's, you know, I don't want to say painful because I don't feel that much pain about it, but it's

incredibly obvious his issues and that he's totally different from them. And so he's different from every other kid that I know that's his age. He doesn't do any of the things that they're doing. In some ways it is good, but in most ways it is negative. (son has genetic condition with comorbid health issues)

Interactions that resulted in parents forming comparisons to other children of the same age exposed the developmental, social, and emotional differences with their child.

Because of these differences, parents were challenged to form new understandings of “healthy” and “normalcy.” For instance, one mother whose son was currently hospitalized for medical procedures pertaining to his cerebral palsy stated:

My gauge on how well he's doing is much different than on anybody else. I mean compared to many other people he's not doing very good – ever really... When we got to the hospital this time, it kind of was just an eye opener that anytime he gets sick it could put him at a different baseline—a different normal.

Even if a child was not hospitalized, parents stated that their child's increased susceptibility to other health problems and compromised immune systems required them to redefine what normalcy and healthy meant.

The differences stemming from a child's chronic condition required parents to manage care differently for their chronically ill children compared to their “healthy” children. For instance, parents reported being more vigilant and concerned when any health issues surfaced with their chronically ill children. For instance, one mother stated:

He gets a hit to the head or you know somewhere...he gets an injury or something really where it hurts... [The doctors] have to do MRIs, CT scans, and X-rays to look for those bleeds, so every time something happens we're in the hospital. With a normal kid, like with my daughter, they wouldn't have to do that 'cause it was just a bump. (son has hemophilia)

As she conveyed, many parents had to go to the hospital or seek immediate medical attention when minor health issues surfaced. Thus, caring for children with complex chronic conditions was described, as “cumbersome” and “challenging” because of the

caregiving responsibilities required from parents, as well as the differences in monitoring their child's overall health.

Parents' acknowledgement of differences also influenced how they parented their children. One mother with two children explained the differences between parenting her daughter and her son:

The lows of being a parent to [my daughter – child with chronic health condition] are a little lower than with [my son who does not have a health condition] because usually they're a little closer to life and death. (Laughs) Um, but the highs I think are even higher sometimes because every time she does something it's like I didn't take that for granted. I didn't know if that was going to happen. (daughter has genetic condition with comorbid health issues)

Differences stemmed from the caregiving needs required from their child's condition that made it difficult to be a "normal" parent, even regarding day-to-day parenting issues. The same mother, whose daughter has a genetic condition with comorbid health issues, expressed some of the recent challenges she has experienced since her daughter became a toddler:

She has all these medical needs, but I also have to be a very normal parent with her. She's a toddler. She's totally pushing my boundaries right now, and trying to figure out what behaviors she can get away with stuff—throwing temper tantrums and needing time outs. It's really hard sometimes to not give in to her because first of all she's got medical issues. For instance, she throws a temper tantrum and she has her speaking valve on at the time. And that's a hugely complex situation right there. I can't walk away from her because she's got her speaking valve on and that's... She has to have one on with supervision with it, but I don't want to take it off because then I'm like removing her voice then that's not fair. She's in the middle of expressing something to me right now and so it's very complicated... When she does something naughty part of me is like, "yes! (laughs) 'Cause it's great to see that normalcy from her."

As this mother stated, parents had to wrestle with being a "normal" parent, while simultaneously attending to their child's health needs. The meanings that parents assigned to these differences often required them to acknowledge the limitations that they

had as caregivers and parents because of the uncertainties associated with their child's condition and parents' inability to control everything. For example, one mother expressed the hardships she experienced by trying to be a "normal" mom for her daughter. She recognized that the limitations stemming from her daughter's condition prevented her from doing certain things that other mothers are typically able to do for their children:

While we are still her parents, we have no idea what's going to make her better. [The doctors] do. And you know normally a parent has all that ability to say, "I love you. Hold her and she'll stop crying." (daughter has heart condition)

Similar to this mother, other parents' meanings about the differences with their child and their role as parental caregivers was influenced by larger perceptions of normalcy and the comparisons made between others and them. These comparisons also affected parents' assessments of hope and hopelessness. One mother described how she assigned meaning to the different information she sought out and received from others:

I'm trying to stay ahead of the game. I've tried to kind of connect with as many professional epilepsy organizations, again being careful of where I get my information from and not reading too much about negative examples or horrible statistics so as to not get into this panicky, hopeless state. (daughter has epilepsy and son has mental illness)

Thus, parents' information seeking and meanings assigned to differences influenced their comparisons that affected their assessments of hope and hopelessness, and how they constructed normalcy.

### **Acknowledging Chronic Uncertainty**

At the exterior of the model (see Figure 1) is *acknowledging chronic uncertainty*. Regardless of a child's diagnosis, parents described how the treatment period was pervaded by chronic uncertainty that encompassed every aspect of daily life. As one

father stated:

It's kind of everyday... With a situation like this there is no magic date on a calendar that you can circle. Uncertainty is kind of the overriding feeling. (two children have genetic condition)

Heightened and perpetual feelings of uncertainty existed for all of the parents because of the complexity with their child's condition. This complexity stemmed from a variety of factors, including: life-threatening diagnoses, heightened severity due to current hospitalization for treatment, increased challenges because of co-morbid health issues, unclear treatment plans, or rare genetic diagnoses. The few parents that had children with less severe diagnoses that had an established treatment regimen (e.g., Type 1 diabetes, Hemophilia, Down Syndrome) still talked about heightened uncertainty arising from current complications with their child's health. For example, a father with two infant children who had Down Syndrome described how the "uncertainty never ceases."

Uncertainty always existed, but the degree of it was dependent on how his children were doing physically, mentally, emotionally, and socially. For his family and him, the current state of uncertainty was heightened because one of his children experienced complications from surgery:

You run an echo. Okay that comes back fine. They do this test and that comes back fine. Their kidneys are fine. And then all of a sudden they do blood work, and all of a sudden she has transient leukemia and does that sound scary. Apparently if it had been in "a typical child," when they initially did the blood work they would have started treatment for leukemia right away, but with Downs children you can't.

Even when children were not hospitalized for treatment or surgical procedures, managing a child's condition and treatment at home still presented ongoing uncertainties for parents. One mother with a son who had a complex genetic condition with comorbid health issues stated:

It's been hard... As time went on from that point to this point he has the grid two deletions. He has panera cerebellar hypoplasia, which is his cerebellum didn't grow, so he just has a large space with a tiny bit of cerebellum in the back of his head. His brain stem is smaller than it should be which makes for the motor skills and the coordination to be thrown off because it's more congested trying to get the neurons and stuff through the spinal or brain stem. He has scoliosis. He has chronic lung disease. He's got a dysmotility of the esophagus. He's got GI track. He has SPT, which is Supraventricular Tachyardia of the heart. Um, he has low tone hypoternia. He still has that. He has osteopenia, which is brittle bones. Um, he's got neuropathy so he can't move... So you see everything is unknown and becomes more uncertain as we learn more about his condition.

As parents described their different uncertainties and the pervasive nature of it, this talk centered around three issues: feeling heightened emotions, waiting endlessly, and questioning the future. A description of each theme within uncertainty is included with quotations from parents to provide a glimpse of what they discussed.

**Feeling heightened emotions.** Parents experienced many different emotions amidst the chronic state of uncertainty. Parents used emotionally-valence words to describe their experiences including: “scary,” “difficult,” “worried,” “frustrating,” “unpredictable,” and “exhausting.” Parents’ use of these emotional words often derived from interactions, such as hearing difficult news from medical professionals. One mother, in particular, provided a detailed account about a time when her son’s physician said that he was going to die from his brain tumor and the family needed to make preparations. As the weeks progressed, her son ended up not dying and is still living (i.e., fifteen years after receiving the original fatal prognosis). She recounted that the time leading up to her son’s presumed death was some of the most difficult moments within his treatment to date, but the uncertainty became even more unbearable the following months after he did not pass away:

We were told that he would die in seven days. And then when he didn't, I guess [uncertainty] started to come when he didn't and then [he] just kept going and

going and going (i.e., referring to still living). That was really hard. (son has comorbid health issues from brain tumor)

Situations such as this resulted in emotional roller coasters, in which parents had to prepare for extreme measures and constantly live in chronic uncertainty about the future.

Making medical decisions was another emotional experience that parents described as being hard, difficult, troubling, and stressful. The most difficult decisions involved life and death matters, and even after decisions were made fear and panic would ensue because of the constant uncertainty about the future. One mother described an instance in which she and her husband had to make life-saving treatment decisions for both of their children with a rare life-threatening genetic condition that causes cellular damage:

We just desperately wanted him to live until Christmas and his birthday. So we had a phone team meeting and made the very difficult decision to give him this medication—a med that nobody believed that was safe for him... And signing that paper that we knew we were giving our son a dangerous contraindicated medication was really difficult. And when it started dripping in, the panic that set in that you know, “What have I just done?”

During moments such as this, parents questioned medical decisions made for their children and wrestled with myriad emotions.

Even when difficult decisions did not need to be made, the general hardships with managing and coordinating care added to parents’ descriptions of negative emotions. For example, one mother who had at-home nursing care talked about the emotional challenges with ensuring that the care she desired was provided to her daughter:

Some of [the nurses] are very by the book and they said, “We need documentation saying that we can do it this way.” It just gets very frustrating because everything has to be written down; everything has to be signed off. And you feel like you're kind of losing control of her being yours still. (daughter has heart condition)

Frustration also stemmed from not having a clear treatment plan because of comorbidity

or treatment ineffectiveness. Several parents had children who did not have a clear treatment plan, including a mother with a son who had a heart condition and cyclic vomiting syndrome. She regarded the uncertainty about treatment as the most frustrating part of her son's diagnosis:

I think that's the most frustrating thing about his diagnosis is that there is no, "this is when this is going to happen and this is when this is going to happen and then this is when this is going to happen."

Most parents had children who had been living with the diagnosis for several years. These parents discussed how new challenges would surface as children achieved developmental milestones. The most frequent new challenges described by parents were the transition to school and the transfer of treatment responsibility from them to school educators and their child. One mother shared her fears about her daughter becoming a toddler and beginning preschool:

I think it's scarier the older she gets because the more aware she is of everything that's going on...It's going to be interesting the more socialization she gets—how that's going to impact things. It's hard to think of, you know, how mean other kids can be. That's a whole level of stuff [my husband and I] have not had to at this point deal with before. (daughter has genetic condition with comorbid health issues)

Another challenge that was stressful for parents involved maintaining daily life. Often times, money and finances were mentioned as significant stressors that surfaced while managing daily life alongside their child's condition. If a child became hospitalized, parents reported that their stresses and anxieties increased, and new challenges emerged with managing life back at home and life at the hospital. For example, one mother conveyed all of the challenges she faced as her son was hospitalized for tests to determine an effective treatment plan:

I'm all stressed out because I've got to pay eight hundred dollars for a house that

I'm not even staying in right now, and trying to feed us here, and keep good hygiene while we're here, and thinking about my other son and school, and getting the things he needs for school while I'm away. It's been stressful. (son has genetic condition with comorbid health issues)

Outside issues (e.g., other children, job) were emotionally and financially straining, and added to parents' descriptions of negative emotions. In an attempt to work through these emotions, many parents mentioned sharing their challenges and emotional hardships with the other parent, or confiding in other family members (i.e., adult parents) and friends. Parents' support networks provided them with an outlet to express negative emotions. For instance, one mother talked about whom she confided in when she was distraught and emotional:

When I have a moment with one of my friends, I'm like, "Okay I'm freaking out today because now we've got CVS [i.e., compulsive vomiting syndrome], now what are we going to do? Or I'm freaking out today because [my son] is not eating and he is underweight, extremely underweight. Or I am freaking out today because he was misbehaving today and now I feel like the worst mother in the world." (son has heart condition)

**Waiting endlessly.** One of the hardest challenges with the treatment period was the endless waiting. Parents described waiting as a "game" that was a "long slow process" and felt like "purgatory." A time that involved extensive waiting was when their child was hospitalized. During this time, parents talked about vigilantly waiting to determine whether their child would be healthy enough to return home. Often, minor health issues such as a fever would surface and result in major complications or setbacks that caused families to remain in the hospital longer. One mother described her own experiences with waiting:

She was healthy two weeks after surgery. She was ready to go home. And then she had a fever for no reason. And then now she has chest tube for no reason. [She] did surgery so well, but this is what we got... That's what made this stay so hard. (daughter has heart condition)

Parents used several analogies to depict what it was like to wait in the hospital.

For example, one parent whose son was awaiting a bone marrow transplant stated:

It's like, "who moved my cheese?" We haven't found the cheese yet, but uh, we're getting little crumbs here and there on the way to finding it. (mother, son has severe aplastic anemia)

Parents reported that medical professionals communicated these analogies to them during meetings. Parents then reported sharing these analogies with other people when talking about their children. For example, one father who was a teacher used several analogies when talking with his principal or students about the constant uncertainties and hardships he faced while caring for his two children with a rare genetic condition. He recounted what he said in a recent conversation with his principal:

I don't know if I want to call it a game you're playing, or you're trying to play [a game] where they keep changing the rules. It's just like, I'll play the game. I'll do what you want me to do, but just don't change the rules for a really long time. Let me do this thing—this hard thing really well... But the reality is that [certainty] isn't going to happen.

As this father expressed, for most parents every aspect of current and future life remained uncertain and involved waiting.

Part of the challenges of the waiting period was the continuous and amorphous nature of it. Parents had to wait to receive a diagnosis, determine an effective treatment plan, and monitor ongoing and emerging acute or chronic health issues. All of this waiting occurred alongside their other responsibilities (i.e., caring for other children, job) and daily life. Further, constant fluctuations in their child's health or development resulted in endless waiting. Thus, many parents reported extreme frustration from having to wait, as stated by one mother:

So I think the most frustrating thing is there is not a timeline. It's like for the first

four and a half years we've been waiting, just waiting for the cardiologist to say, "okay, it's surgery time." (son has heart condition)

Even if a child's current prognosis was not terminal or life threatening, the future outcome of their child's condition and quality of life remained unknown. As a result, many parents felt like they were on a roller coaster—sometimes things were going well, while other times things were terrible. All parents, to some degree, expressed similar sentiments.

Parents whose children were nearing the end of in-hospital treatments still talked about the challenges with waiting at home, even after treatments were about to end or already complete. One mother whose daughter was nearing of the end of chemotherapy stated:

My concern and uncertainty is how are her organs going to hold up, how are they going to hold up in life?... At the end of these three months it is not a done deal. It is month-by-month bone scans, chest scans, wondering about the organs... We just wait to see. We have scans to see if it comes back. It has a tendency to come back in the side next to the prosthesis where the bone used to be or in her lungs. And so she'll get body scans and lung scans to see if it comes back... So, my trial of uncertainty comes from these next three months and looking ahead not sure if we're going to get to the end okay. (daughter has cancer)

For this mother, the her daughter's future outcome would not be revealed until months or years later, after tests and procedures were complete. Thus, parents, such as this mother, felt like they were constantly waiting, whether they were waiting at home or in the hospital.

**Questioning the future.** Chronic uncertainty resulted in parents questioning the future. Parents with children who had co-morbid genetic conditions expressed even more questions because of the lack of information about their child's diagnosis, effective treatment regimens, and uncertainties regarding quality of life. One mother detailed all of

her son's chronic health problems to date and presented several questions that she and her husband had about his condition and future life:

So, which of his basic skills will he achieve? Just to repeat some of them, it's walking, talking, self-feeding, dressing himself, toilet training. I'm incredibly afraid of [toilet training] with him. I have no idea what that's going to be like. And then the other huge question out there is what will school look like for him? You know, when will he be ready for school? When he's ready, what type of school is he ready for? Where will that be? A kid that is blind with no other issues would go to a school of the blind. That's not even anywhere near our house. He probably would be at boarding school if that is what's appropriate for him. If it is not [appropriate], we would love to have him at Catholic school, but that's probably not on the table. If he was in our local public school, what are the programs they have in place? How is he treated on a day-to-day basis? Is he in a regular classroom or is he in a special needs classroom? Does he have an aide?...It is all one big question. (son has genetic condition with comorbid health issues)

Amidst these types of questions, parents talked about the future being a "guessing game" in which many of the unknowns would continue to remain unknown.

For health conditions that had a clearer label with a more defined care plan (e.g., cerebral palsy or Type 1 diabetes), parents still reported having a host of questions about daily living and how to provide sufficient care for their child at home. A mother to a 17-year-old son with cerebral palsy provided insight into the plethora of questions she had about the adaptations necessary for her son's daily living needs:

All the little tiny things you have to think about: like will I hire someone to come and change his toothbrush head? Sometimes his toilet clogs, but he can't take a plunger and plunge that. You know, do I hire someone? If it's in the middle of the night, do we have a maintenance man? How does this work? So there's all these kinds of things that you have to figure out in just daily little situations in your life... And the uncertainty is that you don't know these things until it happens because you can't predict every little thing in your life.

Part of attending to their child's daily needs left parents with questions about administering treatments at home. One mother talked about the questions that she had with managing her son's condition at home and who to confide in about questions:

[The doctors] do everything to train you and to keep you involved and stuff like that, but it's just when you get home it's just like this big ordeal... There's so many numbers that I don't even know who to call sometimes. (son has congenital hyperinsulinism)

To some degree, all parents expressed similar questions surrounding daily living and care management, whether their child was currently hospitalized or living at home. These questions were ongoing as children aged and new challenges surfaced. Parents had to constantly communicate with their child, the other parent, or health care professionals in an attempt to navigate these questions and make decisions that provided the best care possible. For instance, one mother recounted her experience with managing her daughter's epilepsy treatments at home and the ongoing conversations that she has with her daughter's physician:

She's on two medications... after we were told that she did not have a cancerous brain tumor, they needed to increase the second one to the maximum amount that she can be on. That second [medication] in some children causes side effects – and not all children – but it does in her. We have to go in and have her blood work done and have her liver function tested. I get test results like right away and then I look at them online. Then I'm calling in, "Can we watch this please?" [The doctor says,] "Yes, I'm watching it." But, kind of at my prompting because I kept watching the numbers rise. I was like, "I don't want her to have liver damage. I don't want her to have seizures either. We got to do something about this." So, [the doctor] did, she said "there is something I can put her on to protect her liver." So they put her on that third medication to protect her liver, but, that medication makes her smell—like bad. (daughter has epilepsy and son has mental illness)

Questioning the future pervaded the treatment period, particularly if a child's health issue required in-hospital medical treatment. For more severe cases of illness that did not have an established treatment regimen, parents expressed questions about how to proceed with medical care. As one mother to a child with a severe heart condition stated:

[My husband and I] never know what our next step is. A lot of kids probably have four surgeries that are coming up like the Norwood or the Glen. Every surgery has a name and it's always different for each kid, but there's always a step. And for our [child] there are no steps. We go to her appointment each month, take an x-

ray, and pray that there's nothing on the x-ray and that everything's good and that we can go back home. That's it. We have to bring a change of clothes with us when we come because we just never know if we're staying the night that night. And that's how it is every day, too. We could go to sleep and the [in-home] nurse could wake us up and say, "something is going on. You need to go to the hospital."

In instances such as this, even medical professionals were not able to provide parents with clarity or reassurance about the future. One mother, whose two children were diagnosed with a rare genetic condition, talked about some of the communication challenges that occurred with medical professionals when questions remained unanswered:

There's a lot of questioning and that's what's been really, really hard. The physicians don't understand the process of this disease, don't understand what it does... And still in our area when [my husband] brings our kids in and [the doctors] are like, "what's their diagnosis?" They look at my kids with like a myriad of issues and yet really look pretty amazing, and they're like, "what in the world?" We're like it's mitochondrial disease. They're like, "mito what?" [The doctors] don't have any idea and they go out and consult doctor Google and come back and think they are an authority. So, it's a little bit of a learning curve.

Thus, the complex and unique nature of many children's conditions created a host of questions about the future for both parents, as well as the medical professionals.

Unanswered questions about the future led parents to remain uncertain about how to talk with other people and ask for help. In instances where other people would inquire about their child, parents did not always know how to respond and remained speechless. As a result, parents would either provide a blanket response or redirect the conversation towards another topic. One mother whose son had cerebral palsy recounted a recent conversation that she had with some extended family members:

[My family] went bowling Wednesday and my uncle said, "hey, so how's Jacob doing?" "Oh, he's doing pretty good." (laughs) And really I mean he just had some of his worst X-rays of his life. His left lung is completely full of liquid of some kind or another and he might need to be on a ventilator the rest of his life.

So it's not really well, but hey, I don't really know what else to tell [my family]. I mean, if we told them all those things would they understand?

Part of parents' uncertainties with having these conversations stemmed from not fully understanding everything about their child's condition and/or treatment plan. These unknowns made it difficult to know what to disclose or how much information to share.

### **Constructing the “New Normal”**

The chronic uncertainties characterizing parents' lives led them to describe their current lives as permanently different, new, or changed, particularly in comparison to life before their child's chronic diagnosis. As one mother with a daughter who has an eating disorder stated, “Your everyday lifestyle has changed. Your world is operating and functioning differently.” Parents described how a life characterized by chronic uncertainty meant that life, as it once was, would never exist in the same fashion because of the daily treatment regimens, medical procedures, and increased hospital visits that were now incorporated into their family's daily routine. Thus, the “new normal” was demarcated as a constant dealing with a child's illness and all of the requirements and uncertainties associated with it, in a way that was now typical and transformative in comparison to a family's previous life. Parents reported that *constructing the “new normal”* allowed them to navigate uncertainty and redefine what it meant to be normal. Many parents reported a desire to transfer this meaning to their child, as well as other family and friends, so that other people also understood the “new normal.” Parents' organic use of the words “normal” and “new normal” in their accounts of uncertainty, hope, and hopelessness demonstrated their acceptance of normalcy as being important, and also acknowledged the ongoing changes within their families that lead to the “new normal” and what was required to maintain it. Constructing the “new normal” was

qualified by two themes (i.e., making changes and striving for normalcy) that are described by using parents' quotations.

**Making changes.** Life was changed or altered because of a child's chronic condition and the ongoing demands associated with providing constant medical or pharmacological treatment. Changes varied from moving to a new city for treatment programs to altering dietary patterns within the entire family. The need for such drastic changes occurred because all of the parents had children whose medical conditions required increased hospital visits or ongoing treatment regimens. Whether in the hospital or at home, parents had to restructure their family's life in order to keep the focus on their child living with the chronic condition and attend to his or her needs first. One mother whose daughter was going through chemotherapy expressed:

Our schedule and our focus has definitely changed. Our schedule being that we don't have a whole lot of extracurriculars going on anymore. We used to be in ballet, we used to go to the Y more. We always had something, just sort of an extra thing to do on the schedule. Well, everything's off the schedule. You know, it's pretty much day by day, and [my daughter] has become a big part of our focus. Trying to keep her memories going, and have positive things to look forward to, and then also trying to meet the needs of the other kids too. (daughter has cancer)

The entire family's life now operated on a day-to-day basis, as most of the other parents similarly recounted. Most significantly, changes resulted in life now operating on a day-to-day schedule, as well as parents' need to discard or re-evaluate previous goals and dreams that they had for their child and family. This occurred because of the current circumstances surrounding care and potential debilitations resulting from their child's condition. One mother talked about the changes that she and her husband had to make because of her son's cerebral palsy:

It's a lot different than what we thought... I mean, even schools. I remember

when we were in our like, pre-K [i.e., marriage preparation class] thing and we thought, you know, our kids are being brought up Catholic and going to Catholic schools and doing all this... Well, that was shot out right away because the school administrators told us he was better off in public [schools]. Um, so you know, those kinds of things really changed.

Thus, the increased hospital visits and strict treatment regimens changed hers and other families' lives permanently. Since most of the parents were married, they mentioned talking about these changes with the other parent in order to make decisions about the future and coordinate a child's care alongside the day-to-day living needs (e.g., work, attending to other children).

Initially, making changes was described as difficult or shocking; however, parents discussed reaching a point where the life adjustments and changes became part of the "new normal" lifestyle. One mother whose son had congenital hyperinsulinism talked about how her family adjusted, over the course of several months, to testing her son's blood sugar several times daily:

When [my husband and I] first went to the hospital we had a nurse come to help us with [testing our son's blood sugar] because it's really hard to poke your child and get a sample... We would keep track of every single sugar we took. You know, be on the phone with daycare during the day to see what was going on. And now that we've been doing it for several years it's a lot more like, this is our life. Like, you know, he gets his meds, and we check his blood sugar, and we make sure he eats. And it works... He's used to it now too... When we go in the morning to get him. He tells us to turn off his white noise machine and then he sticks out his figure. So he knows that we have to prick his finger next.

Parents like this mother became comfortable with administering treatments at home and integrated these necessary tasks into their "normal" routine. Time was a critical factor that helped parents to accept the new changes as part of the "new normal." One mother whose daughter had a complex genetic disorder that affects the nervous system and a child's ability to communicate verbally, described how time helped her accept the

constant changes her family experienced:

I think that it's absolutely unrealistic to expect yourself to get used to your new normal in any short amount of time. You can't. You absolutely cannot. And if you say you can, you're setting yourself up for failure. You need to give yourself time... I think we're all, you know, more um accustomed to what it means to be Mary. Our family has learned her way of communicating. You know, we all know that we have to pay attention to certain... You have to pay attention to her more than you do the other kids.

For most parents, time provided hindsight and perspective to be able to compare current circumstances with the past and recognize their abilities to function within chronic uncertainty.

One significant change that many parents had to accept was increased hospital visits and in-patient treatments, particularly when problems with their child's condition surfaced. One mother whose son had a severe case of obsessive-compulsive disorder (OCD) detailed the sacrifices that she and her husband had to make over the course of several years:

We had to change our life at the time. [My son's] OCD came into crisis. I was homeschooling. My husband was working full time. The two of us also, um, directed the youth ministry at our church. That was kind of a part time job for us, and it was a paid part time job. But when his OCD came into crisis we had to let [directing youth ministry] go because [our son] just needed too much attention from us.

Although they had been managing their son's condition for over 8 years and attending various therapy programs back home, the severity of his condition had exponentially increased, which required them to travel across the United States for a specialized in-patient treatment program. After being in the program for several months, the parents started to see some significant improvements and the mother mentioned sharing these positive changes with her husband who was tending to other life responsibilities at home:

I came here saying to my husband, "I can't go back and homeschool next year if

nothing's changed. I can't do it. It's just too overwhelming."... But now, I'm really beginning to see some changes. He's really, um, been doing ERP (i.e., exposure response prevention therapy) every day like he's supposed to... And, um, he is able to handle things a little more. He's able to, um, if he gets stuck by a thought or obsession or something that would normally throw the whole day away, he's able to recoup and recover himself a lot quicker. (son has obsessive compulsive disorder)

Not all parents were as fortunate as the parents above. Some parents had indefinite stays at the hospital in order to determine an effective treatment plan or monitor symptoms that increased in severity. Many parents described how these extended hospitalizations occurred on a semi-frequent basis. One mother, in particular, whose child had spent most of his life in the pediatric intensive care unit (PICU), stated that although it was an emotionally difficult place to be, the hospital had become her new home:

[The doctors] get mad at me sometimes because they say you do need your sleep... But, this is my life and this is what I'm used to. This isn't my first hospital go around. This isn't my first rodeo. This is what our life is. (mother, son has genetic condition with comorbid health issues)

Most parents recounted similar moments in which the changes required during their child's hospitalization or treatment completely transformed how day-to-day and future life functioned.

**Striving for normalcy.** As parents talked about the changes, they simultaneously mentioned striving for normalcy. Normalcy, however, was often unattainable because of the necessary changes that characterized daily living. As one married mother with several children, including a daughter who had cancer, stated:

So I guess the biggest struggle is keeping her life as normal as possible, and keeping all the [other siblings'] lives as normal as possible.

As this mother expressed, many parents regarded their desire for normalcy being a constant struggle and reported an even greater desire for normalcy when their child was

hospitalized. During this time, family life became so disrupted that any sense of normalcy seemed impossible, albeit a continuous desire. For example, one mother recounted what she noticed from other parents who also had children in the same in-patient treatment program as her daughter:

There have been several parents walking around with Bluetooth's. We are trying to maintain a normal life outside of being here because this is not supposed to be forever. So, you have to make sure that life happens outside of here, but it is hard. (daughter has eating disorder)

All of the parents interviewed who had hospitalized children expressed desires that the hospital visit would be a transient experience that provided the necessary care to their child so the family could return home.

Extended hospital stays required parents to bring the comforts of home to a child's hospital room as an attempt to strive for normalcy. One mother, in particular, talked extensively about the importance of creating a "normal" home environment for her son while he was in the PICU:

Even being in the PICU, as traumatic as it is and as scary as it is, doesn't mean [my son] can't do things... This is home. I'm going to make it home... He watches the Lorax Movie. It's his favorite movie at home. It's the movie we put in when he's upset or when he's just in a mood. I put that on for him. So, I got the Lorax here and I put that on for him... His grandma bought me the book so now I can read him the book that he enjoys so much watching. But it's momma's voice and him interacting with me instead of the TV. (son has genetic condition with comorbid health issues)

Striving for normalcy became more cumbersome when parents had multiple children or the family was displaced in a different city or state for a child's in-patient medical treatments. During these situations, parents not only had to maintain life outside of the hospital, but also had to attend to the needs of their other children to maintain normalcy for them. As one mother with two children stated:

[My son] has frequently felt like [his] life is to accompany [his sister] on all of this stuff... So making the other [sibling] feel like a sense of normal, a sense of home, or this is something special. But, not trying to mask over the fact that this is disruptive. This is not about me... [The other siblings] need distraction and normalcy. So whatever they do at home, whatever the age, and whatever they are exposed to normally... These things really help diffuse everything else. (daughter has eating disorder)

When a child was not hospitalized, parents strived for normalcy by making decisions and lifestyle choices that provided a positive and event-filled life for the entire family, particularly for their child living with the chronic condition. For instance, many parents would take their child on vacations and attend sporting events, so as to give them the same opportunities as other “normal” children. Although these opportunities often required extensive planning, parents reported that they frequently provided these opportunities for their child. In fact, one mother described how she and her husband took their daughter who was on a ventilator to the lake:

We treat [my daughter] like a normal kid as often as we can. We take her on vacation and people are like, “you took her in the water, are you crazy?” Yep we are!... Her five thousand dollar ventilator is by the water. (daughter has heart condition)

She expressed that it was important to let her daughter “feel normal” and not place too many restrictions on her life, particularly given her terminal prognosis. A different mother, whose son’s condition was not terminal, expressed similar sentiments:

[His condition can result in] some sort of sad life if you bundle him up and don’t let him out. And his doctor said, “absolutely not, don’t put him in a padded home... Let him be fine. When he doesn’t have a bleed, let him feel normal then.” (son has hemophilia)

Parents stated that many doctors affirmed the importance of striving for normalcy, despite the limitations or ongoing adaptations required from a child’s condition. Subsequently, many parents actively sought out opportunities for their child to feel more

“normal.” One mother described how she got her daughter involved in a camp to normalize her experience with Type 1 diabetes, particularly because she was so young in comparison to other children with diabetes:

It’s really a fluke to find kids this young diagnosed with it and being able to deal with it—usually it’s a little bit older... So, we try to make it as much mainstream as we possibly can... She got to go to a camp this year that was just for kids with diabetes... They would just do drills and then they would have snacks... Okay it’s time to test and everybody sat down... You know, and to see them be like, “hey let’s test.” Everybody was pulling out different meters. Everybody did different things. People were using pumps; people were using syringes. It was just neat for her to see different kids doing the same thing. It wasn’t abnormal at all.

These opportunities provided glimpses of normalcy that parents identified as crucial for coping.

Normalcy was sometimes difficult to achieve given the ongoing health changes with a child’s condition. For example, one mother talked about how their normalcy changed as the severity of her son’s condition increased:

When he came home, we came home to nurses in our house for three years. It was just a new normal to have a child on life support. People say this all the time, “if I’m ever on a ventilator or if I ever have to be on life support, cut me off.” I remember thinking, “wow, that’s not always true.” Here he could only smile. He couldn’t walk, talk, eat, sleep, or swallow. He was bed-ridden, but he was happy. (son has comorbid health issues from brain tumor)

Changes, such as this, required parents to remain flexible, knowing that striving for normalcy was an ongoing process that may need to be continuously redefined and navigated.

Finally, parents discussed the important role that other family members and friends had in helping them strive for normalcy amidst ongoing changes. These other people were crucial in creating a “normal” life for their children. For example, one mother whose son had a complex genetic condition with comorbid health issues talked

about how her mother provided opportunities to her and her son that helped normalize their family's life and her feelings about his condition:

The best thing that my mom has done is treat Adam just like any other grandkid that she has...She watches her other grandkids, so she watches this grandkid...She is constantly texting me pictures of the things that he's doing at her house while I'm at work. She has like a little car that scoots along and Adam can hardly sit up. He can't bring himself to sitting, and he can't see to scoot himself around or understand the concept of scooting around. But, she still puts him on the car and takes a picture and sends it to me: "Here's Adam playing with the car." She stands him up in the windowsill to practice standing and has him looking out the window and sends me a picture: "Here's Adam looking out the window," like any other kid.

### **Feeling Hopeless and Maintaining Hope**

The central process of *comparing self to others* influenced parents' construction of the "new normal," as well as how they balanced the tensions between *maintaining hope* and *feeling hopeless*. Parents' hopelessness and hope were not discussed as isolated, separate concepts, but rather as fluid and dynamic concepts that parents continuously experienced in tandem. For example, one mother talked about the tensions she experienced with hope and hopelessness as her son was in the hospital with a poor prognosis for myriad chronic health issues:

I get emotional because I see both sides of it. My youngest one will never be able to go to school. He's got a low immune system, so he could never be around many other people. And it's sad because I think of him not getting invited to his first friend's birthday party and having sleepovers, but then I think of all the things I could do with him. Just because his friends can't do it doesn't mean mom can't do that. (son has genetic condition with comorbid health issues)

Like this mother, other parents talked about hopelessness and hope together, although the descriptions that parents provided about each concept was different. Hopelessness was described as a reactive, emotional feeling that included experiencing overwhelming obstacles, dreading the what-ifs, and suffering from anticipatory grief. In contrast, hope

was discussed as an active choice that was communicatively and cognitively maintained by finding a supportive community, relying on religious and spiritual beliefs, and reframing towards positivity. Each of the tenets of hopelessness and hope are presented with parents' quotations included in the descriptions. The three themes denoted within parents' feelings of hopelessness are presented first, followed by the three themes characterizing parents' abilities to maintain hope.

**Experiencing overwhelming obstacles.** At some point during a child's treatment period, parents experienced disappointments or obstacles that led to feelings of hopelessness. As one mother described: "each hurdle you get over, there's another hurdle waiting" (daughter has genetic condition with comorbid health issues). For hopelessness to ensue, these hurdles had to be perceived as overwhelming. Money and finances was one overwhelming hardship that was a source of hopelessness for many parents. In regards to this issue, one mother stated:

The money piece of it is really hard. That's the frustrating thing. Like okay, we met our deductible, our out of pocket max for this calendar year. I never really thought that was going to be something we do, like every year. And we only get insurance through my husband's work and the medicine that he's on is really expensive. (son has congenital hyperinsulinism)

Most parents felt overwhelmed by the cost of medical and pharmacological treatments that were necessary for maintaining their child's health and quality of life. Financial hardships were heightened when a child's treatment involved expensive medications, extended hospital visits, or traveling expenses to receive care from medical specialists in other states.

The few single mothers that were interviewed particularly noted the challenges with providing quality care on a limited income and health benefits. One single mother

talked extensively about two specific moments where money complicated caregiving for her son:

I don't make that much. I make almost \$30,000 a year and I have two kids. When my deductible went up and I had to start making the choice of do I lose my house or do I, is the bleed bad enough that I take him in and get it treated? Those were hard. That was awful. I felt very hopeless and very much like a piece of crap... The times that I've had to sit at work, like the one time he hit his head on a pole at school and he had to go in and get CT scans and he was, he was—the school was saying he was losing consciousness and he wasn't making any sense. I didn't have FMLA [i.e., Family Medical Leave Act] time at the time because we were too small of a company and my boss wouldn't let me leave. That was hard. (son has hemophilia)

Amidst financial struggles, parents had to make difficult choices about how they would pay their bills while also affording the cost of expensive treatments. Having to make these difficult decisions left parents in a state of hopelessness. Parents often confided in other people during moments of hopelessness. Sometimes these other people were helpful and other times they were not. When other individuals did not show compassion or understanding, parents described feeling isolated, alone, and hopeless.

Complications with medical procedures or treatments also led parents to report feelings of hopelessness. This was because parents' hopelessness and hope was often rooted in their child's current health and well-being. For example, one mother whose daughter was receiving chemotherapy for cancer recalled a period in which she recently felt hopeless:

She had a really bad reaction to chemo one time and was placed in the ICU for a week and a half. That was probably the worst week and a half of my life... That's when I couldn't think past her sitting in that bed.

Once her daughter's health condition started to improve, she was able to transition out of hopelessness to hope. This transition occurred by the comparisons that she made between her current situation and previous points in her daughter's health trajectory. Other

parents' stated how comparing their situations to other children living with similar conditions also helped them transition out of hopelessness to hope.

Parents mentioned feeling hopeless in instances where comparisons signified that the current situation was bleak in comparison to previous experiences. For example, one mother whose son had cerebral palsy and was hospitalized on a ventilator talked about how this current visit left her feeling hopeless, particularly in comparison to previous hospitalizations:

This trip [to the hospital] was one of my first times of feeling hopeless. And it was because we did all the therapies and we did all the things. [Now, he] looks good and then he looks bad, then good and then bad. [Before,] I feel like there's always been something else to try. [Now,] he's already on a ventilator, like what else to try and what does that mean for him? And what does that mean for [our family]? And what does it mean if we took him off? Like do we just watch him for a few minutes, die? [Before] I wasn't hopeless because there were other things that we hadn't tried yet, whereas this time like we have tried everything.

As this mother stated, parents often situated their understandings about current circumstances into the larger framework of uncertainty. Limited options for treatment and declines in a child's health resulted in parents' expressing hopelessness because of their inabilities to surmount the overwhelming obstacles. Other times, parents mentioned hopelessness ensuing when doctors delivered bad news that altered their previous hopes. One father recounted a time when their doctor called to deliver bad news about his daughter's prognosis and had to clarify previous misconceptions:

And then they called the next day and the doctor is telling me, "I have Michele's results from her lab." I'm like, "yeah, I already got them. Thanks." She's like, "No, I have her results. And uh...the tumor's only fifty percent dead." I'm like, "Nope, I think you've got the wrong person. We've already got [her] results. It was a hundred percent dead." And she's like, "I don't have the wrong person." I'm like, well who's the patient you're talking about? And the doctor goes, "listen to me. I'm talking about Michele." I'm like, "well what about yesterday's results?" And she said it was a mistake. They had two separate samples. They had the outer sample and the middle sample. They'd mistaken the outer to be the

whole thing, so only the margins of the tumor were dead and the whole inside was alive. I'm like, "well what's this mean?" And [the doctor] said, she's like, "this means more aggressive, longer chemo—harder chemo and longer chemo. This will affect her fertility. We're downgrading her life expectancy to fifty percent." (daughter has cancer)

Receiving bad news, particularly when it appeared to come out of nowhere was an overwhelming challenge for many parents.

Other difficult news, as mentioned by some parents, was a lack of clarity from the physician about enacting an effective treatment plan. One mother, in particular, talked about her challenges resulting from medical professionals not knowing how to care for her daughter:

I think especially within the first year of her life as the doctors were still running tests and still not understanding what was going on with her. They'd come back and they would tell us, "she would need this surgery with these pins coming out of her jaw, external fixers, that we'd have to rotate every day to help lengthen her jaw. That was the only way her airway was ever going to be clear enough to be decannulated." And um, then the next appointment they'd be like, "no she doesn't need that." Then the next appointment they'd say, "oh yeah maybe she does." (daughter has genetic condition with comorbid health issues)

The constant back and forth with medical providers coupled with parents' ongoing uncertainty was described as challenging. During these moments, parents reported feeling low, disappointed, and hopeless. Feelings of hopelessness escalated when treatment remained ineffective and parents were presented with signing consent forms and making life-and-death decisions. One father described a time when he felt hopeless because of what his children's primary care physician said:

It was the first time we signed the do not resuscitate papers with [the doctor]. I can see the pen in my hand poised over the paper and thinking, "I can't believe we are at this point where this man who has been in this profession so long, who has treated and lost kids. This is a man who is not new—he knows." And I do not think for one second that he would bring those papers out and present them and propose those papers to parents unless he was absolutely certain that we're heading into this chapter now. (two children have genetic condition)

These conversations were difficult because parents were reminded about the severity of their child's condition and potential fatal outcome.

Even for parents whose children's conditions were not life-threatening and the majority of care was provided at home, hopelessness remained when care burdens were heightened. For example, one father, whose son had intractable seizures for over fourteen years, mentioned the hardships of caring for his son at home and the moments in which hopelessness occurred:

It's over a thousand seizures later, and you know we're still here. We're still going. And um, you know? It can seem hopeless at times. (son has epilepsy)

Intense care demands required constant surveillance from parents to monitor a child's symptoms. Parents expressed feeling hopeless when a child's care left them feeling isolated without any personal time. Several married parents expressed the strain that a child's condition placed on their marriage because of their inability to find a babysitter or someone to watch their child so they could spend time together or have personal time alone. Other parents reported that support often dwindled over time, which left them alone with all of the caregiving responsibilities. When parents desired a break but were unable to attain some personal time, comparing themselves to other parents or outside people in their social networks resulted in feelings of hopelessness. One father expressed some of the hardships that his wife and he experienced in providing ongoing care for their two children at home:

That's really hard. We don't get out very often or you know, so that's another thing that I do find myself [wanting]. Dwelling on [the lost dates] sometimes like I—my coworkers or other people we know it's like you see them on Facebook and they're checking in at this place. You can't do that. (two children have genetic condition)

Limited access to supportive networks was a significant challenge mentioned by the few single mothers who did not have a partner or other parent to rely on for assistance. Even if a partner or other family members were present, medical treatments and surgeries would sometimes require travel that separated families for extended periods of time. During these moments, one parent was left to care for their hospitalized child while the other parent tended to life responsibilities at home. These moments left the parent tending to their sick child to report feeling alone and hopeless. For instance, one mother whose daughter was in the hospital since birth for numerous heart surgeries detailed the hardships she faced, despite reporting that she was happily married and had a husband and two other children who frequently visited her and her daughter:

So it's hard. I sit [at the hospital] by myself and it gets kind of lonely, especially when you've had a hard, long stressful day. I don't always have someone to talk to. (daughter has heart condition)

As this mother conveyed, parents needed continuous support during a child's treatment period, particularly during in-patient hospitalizations, and when this support was limited or constrained parents felt hopeless.

**Dreading the what-ifs.** Because parents lived in a state of chronic uncertainty, questions were commonplace for all parents. However, when parents attended to the questions about the what-ifs or encountered difficult conversations that exacerbated the what-if questions, then these moments were reported as being hopeless. Many of the what-if questions pertained to the future, particularly when their child experienced health complications or was hospitalized. One mother whose daughter was receiving chemotherapy expressed:

And it's been a hard thing just to realize what does this mean and what do we need to be prepared for. Trying to prepare for the future, trying to think ahead,

trying to be a step ahead, but realizing through this whole journey that it really is a day-by-day thing. And you can't—If you think too far ahead it just brings you to the point of tears because you just don't know if you're gonna be—you don't know if you're going to be having to plan for a funeral, or you don't know if you're going to be just dealing with complications the whole way through and there are a lot of them. I mean [the doctors] talk about the heart failure, the liver failure, the kidney failure, the transplants. (daughter has cancer)

For most parents their child's future health and quality of life was a complete unknown.

As a result, all parents reported wrestling with questions about how to best prepare them for the next step or whether their child would survive intense treatment programs.

The what-if questions (e.g., what if my child did not have this condition, what if my child does not make it) often led parents to second-guess themselves and their previous decisions. These types of questions also led to parents expressing fear. For instance, one mother described the fears she experienced while sitting in the hospital room awaiting her son's slight recovery from myriad life-threatening health issues:

I have really demented thoughts that run through my head on a daily basis (laugh) that are disturbing because it's the negative of, "What if this happens?" And the pictures of it if it did happen. And I pray for it to go away. These thoughts are no good to me, they're not going to help me; they're not going to make me feel better; they do nothing for me. So I try to stay clear as much as I can of them. They're never going to go away completely because it's human, you know? Curiosity and what-if's are the human condition. (son has genetic condition with comorbid health issues)

Amidst feelings of fear, many parents sought information to their questions from the Internet and other parents whose children had similar conditions. Although these sources were sometimes helpful, some of the information received increased parents' feelings of hopelessness. This occurred when parents heard or read negative stories or could not find necessary information. In addition, parents mentioned finding information online that was not relevant to their situation, and even if it was the right information they did not always understand how to adequately interpret the information in a useful way.

As a result, statistics and other people's negative stories were sometimes disheartening and exacerbated parents' original fears. One mother described online information seeking as a double-edged sword:

There was a period of time where [research] definitely did not give me more hope and you start to question whether you need to take your child in for a second opinion or maybe you need to go to a different hospital? (daughter has genetic condition)

As parents reported talking about the information they researched online or received from other people, including conversations that they had with their chronically ill child, parents were made aware of their child's own fears. For example, one mother recounted a recent conversation that she had with her daughter:

At one point, she said, "Well mom, if it's just too..." She didn't say prolong the inevitable — but bide time. She said, "If it's just to bide time I'm not interested." And I knew. I mean how can you be seventeen and think that? (Crying) It's just I knew that was what she was thinking. And she just walked away. She wouldn't talk about it. But, I knew that [death] was what she was thinking, 'cause why else would you say that? (daughter has cancer)

Knowing that her daughter had negative thoughts, particularly about death, was difficult, and many parents expressed having a hard time knowing that their child lived in fear of the future.

**Suffering from anticipatory grief.** A final component to hopelessness involved suffering from anticipatory grief. Anticipatory grief occurs when parents live in a period of extended uncertainty and wrestle with negative feelings about death or permanent damage done to their child because of illness (Al-Gamal & Long, 2010). All parents reported experiencing negative emotions that led to grief at some point during their child's treatment period. As one mother stated, "I have my mourning days and I do cry. And when I cry, I cry" (son has genetic condition with comorbid health issues). Although

parents mentioned the initial diagnosis as a time when grief and hopelessness would first occur, parents stated that grief would ebb and flow throughout their child's treatment period. Thus, grief was regarded as a circuitous process. One mother, in particular, detailed her own reflections about her experiences with anticipatory grief:

I think one thing that I've learned in this process is that the process of grieving is not a process. You move forward and you move backwards. (two children have genetic condition)

Although many parents chose to maintain hope, they simultaneously reported staving off anticipatory grief that haunted them and resulted in negative thoughts (i.e., their child's imminent death). For example, parents described periods of crying alone or in the presence of a friend or spouse. These parents mentioned that regardless of how hopeless they felt, it was important to never break down in front of their child, as one mother stated:

There are so many moments of hopelessness. I cry, but [my husband and I] try not to cry in front of our son... My sister came to visit at the hospital and I was pretty honest with her on how I was feeling. One of the nurses that was coming for overnight duty saw me. I was like, "oh my God, he is probably going to be our nurse. He just saw me crying." Because you put on this happy face that everything is okay. You fake it. You just want to collapse but you can't collapse right now because we're in this fight and we can't collapse right now. (son has cancer)

Acknowledging the existence of grief was difficult for many parents to admit to themselves and share with other people. This same mother talked about why she chose to not update her son's Caring bridge site for other friends and family while her son was in the induction phase for a bone marrow transplant:

[My husband and I] are just worried about losing him. And saying that out loud is a really hard thing to say. It's kinda like putting it out there in writing. It's really hard to put this in writing. I know people want to know, but it's hard because I can't put it out there raw. I can't because you can't help me and I can't take care of you. (son has cancer).

Part of parents' grief included mourning the loss of expectations that they had for their child or the future life they desired. Parents would get upset about activities their child could no longer pursue because of physical debilitations. Even "happy" milestones, such as birthdays, reminded parents of the achievements that their child was unable to accomplish. One mother recounted her grief that she shared with other family when deciding whether to plan her son's first birthday:

It's very normal. I mean every, every parent who has a child who has something there's like a little grief that goes with it. Like his first birthday, I didn't even want to make a cake. And people encouraged me to and I'm glad I did. He, he obviously didn't taste it [i.e., due to the severity of his condition]. Um, but it was a reminder to me that he wasn't having any not, "oh we're celebrating his first year." And [family and friends] were like well don't look at it that way. I was like that's how I'm seeing it. (son has cerebral palsy)

Certain events or moments, such as birthdays, would accentuate a child's losses and result in parents' feelings of anticipatory grief. In addition, the presence of having other "healthy" children and comparing their "healthy" children to their child living with the chronic condition often added to parents' reports of grief. One mother who recently had a "healthy" second baby described her own grief in comparing her "healthy" daughter to her chronically ill son:

I mean every parent who has a child who has something. There's like a little grief that goes with it... Like especially when [my daughter – i.e., sibling to child patient] was born, and everything was so easy for her. She just latched on right away and stuff. I was surprised at how much I was thinking about what [my son] couldn't do. (son has cerebral palsy)

At the time of the interview, many parents reported being in the mourning period and experiencing some degree of anticipatory grief for themselves and their child. For example, one mother whose son had a severe case of obsessive-compulsive disorder talked about the grief that she had because of the losses her son experienced:

You almost have to go through a period of mourning. You have to actually grieve for the childhood that you thought your child would have or the life that you thought your child would lead. Because that has, that dream has died. And you almost have to go through a grieving process and kind of finally accept that, you know, your child is different. And your child is not going to do all those things and have those memories or experiences that, you know, tons of kids get. Um, and it's, you know, it's I think harder on the parents than the child because, you know, [my son] really doesn't know what he — the older he gets he knows what he's missing, but, you know, when he's young he just has his own little world. But, we see everything that OCD has stolen from him. So it's really — you really do mourn.

These losses were often accentuated when parents would form comparisons to other children, particularly healthy children who were the same age as their child. One mother recounted some of the conversations that she had with her husband about the grief that she experienced after being on Facebook:

Well, there are periods where you go through, where you see like, um, his peers. You know, like they all went to the dance together, they all got up on this big hill and took a great picture together. [My son] can't do that. You know, he's not gonna climb up on a hill and take a great picture with [his peers]. Um, or, you know, the next thing when [his peers] all got their drivers license and they all, you know, show their pictures on Facebook and their parents are like "look who's on the road." You know, and then you get like (sigh) that should be him. And then you start to think about like, you know, this person's competing in sports. [My son] really wanted to do sports. Then people brag about how their kid's doing great things, which they should and be happy about, but you start to compare your [kid] and be like, what if — you know? What if? And it gets really sad then. (son has cerebral palsy)

As these two mothers stated, parents would often share their anticipatory grief with other people (e.g., spouse, friend, older parent), and these people were instrumental in staving off grief by encouraging them to not form inequitable comparisons.

Finally, anticipatory grief occurred when parents had children with life-threatening conditions. These parents would compare their child's chronic diagnosis to other children with different chronic diagnoses and desire for their situation to be different. For instance, one mother with two children living with a complex and rare

genetic condition that was life-threatening talked about wishing her children had been diagnosed with cancer instead:

When you are told by medical professionals that have been doing this a long time that it's not a question of if, it's a question of when, it's hard — really hard to hear. And it's like, the hardest part at that point was we knew there was no happy ending to this story and no hope. I would have given anything to have that cancer diagnosis because I would have known what we needed to do. And it would have all been laid out because they had already proven treatment and I knew what it meant to be on protocol. I knew what it meant to be off. I knew what it meant to be on study, what it meant to be off. And so it was, I, I knew what to expect. We may still not have had our happy ending, but at least we would have had a chance.

This mother was a nurse and from her previous professional experiences she knew that a cancer diagnosis would have been more manageable due to an established treatment regimen involving chemotherapy and radiation. The lack of information surrounding her children's condition, as well as the life-threatening prognosis, accentuated her grief.

Amidst parents' feelings of hopelessness, they identified several things that improved their ability to maintain hope, including: finding a supportive community, relying on religious and spiritual beliefs, and reframing towards positivity. The three themes facilitating parents' maintenance of hope is detailed below.

**Finding a supportive community.** Parents talked about the significance of finding a supportive community and how the individuals within these communities provided them with a sense of hope that could not otherwise exist. Supportive communities were meaningful because parents were able to express uncertainties, seek information, find acceptance, and receive emotional support and encouragement. As one mother stated:

You can't do it alone. [Caring for my son is] too big! You just need, you know, your friends and your family and your church family or whatever. You just need people praying for you and helping 'cause it's just too hard to handle everything by yourself... [Other people] just listen... like my sister — to break down and say,

“I can’t do this anymore or this is just so hard.” And, you know, um, just having them say like, “yeah I know it is,” is helpful. I don’t know why that is, but it is. So just being able to be honest and real and, you know, not put on a happy face or like oh everything’s okay. It helps to be able to talk about what you’re going through — it just helps. (son has obsessive compulsive disorder)

As this mother recounted, social support provided parents with opportunities to confide in other people that helped them receive the tangible aid, encouragement, and empathy they needed.

Given the numerous positive benefits that parents reported from having a supportive community, many parents actively sought out individuals who could be credible sources of information and provide positive encouragement. Often, other parents or their children living with similar conditions were mentioned as the supporters that instilled the most hope. One father talked about his search in finding another girl with his daughter’s same condition and how her story provided him and his wife hope:

[My wife and I] have been trying to grasp to any hope that we could find since we found out she had this. So we’re looking for, we’re looking for information and everything like that. I mean, there’s a wealth of knowledge out there. And we’re thinking, okay, maybe there’s people on Facebook that have this that are trying to tell their stories of how they’re leading lives. We wanted to see what people, how they’re acting, and how they’re doing so we could get hope. And we did, we found them. You know, they’re all over the place... One in particular, she’s probably twenty-five now, I’m guessing, but man she loves life. And she, like, goes skiing and snowboarding, and all these cool things. She used to be in gymnastics. I just point her out, but people like that give us hope that [our daughter] can do that someday... We get a little crutch from them. (daughter has heart condition)

Parents found these individuals and communities online or sought them out face-to-face. Because many of the parents resided at the Ronald McDonald House Charities, this living environment was also mentioned as a significant supportive resource that assisted parents with maintaining hope, particularly by granting access to other families going through similar circumstances. For instance, one mother shared the support that she received by

interacting with other parents staying at the House:

Just meeting the other parents and seeing the other kids, and seeing that somebody always has it worse than you do. I ran into a guy that's been here since February, last year. I was like, "it's only January." He said, "since last year." So you know, meeting and taking strength from some of the other parents and kids that you meet. For me it's very helpful. (son has cancer)

All parents regarded other parents of children living with similar health conditions as a unique and credible resource because they were able to personally identify with the joys and challenges of having a chronically ill child. Parents vigilantly observed how these other parents coped with their own child's diagnosis. One mother, in particular, described the positive influence that another mother had on her reaction towards her own son's condition:

When [my son] was younger and he was about to go through heart surgery number two we met a family that had three boys — twins who were 8ish and another boy that was like 6. The 6 year old and one of the twins both have the exact same heart defect as [my son]. And I was blown away by the strength in that family. I never saw her broken even when her 8 year old was in-patient at the time. One of her twins, even when he wasn't doing well she was just, "we're good. Don't worry about us, you know." And it baffled me. It gave me a lot of hope. She gave me a lot of hope that you could indeed get through this with a smile on your face, that you could do that. It was possible because before her I wasn't so sure. (son has heart condition)

Parents were inspired by these other parents and relied on them for emotional and informational support. Sometimes this included gleaning information about treatment plans and how to make medical decisions for their own children. Other parents were often described as being a "knowledge base" and "lifeline," and parents trusted that these other parents would offer good advice. This information was particularly useful for parents with children whose conditions were rare. These parents relied upon online communities to access information that they could not obtain elsewhere. Such sources were often viewed as more credible than the health professionals treating their child. For

example, one mother expressed the importance of her Facebook group:

There's not a ton of kids around [The Ronald McDonald House] so being able to talk to 200 families at once, or to ask a question and have it be answered by people that have gone through this has been really the most helpful... I remember asking the question on there like, "what if his blood sugar is in the 200's, is he going to be okay?" Other people [on Facebook] were like "no, when my kid has a virus the same thing happens. That's actually a good response that his body is making his blood sugar go up." (son has congenital hyperinsulinism)

Without communities such as Facebook groups, parents felt like they would be isolated and unable to form equitable comparisons to assess normalcy. Further, parents' maintained hope by hearing other parents' positive stories. As one mother noted:

And I'm on a couple support groups on Facebook...just knowing that [the people in the group] have gone through surgeries, their babies have gone through surgeries, and they're four years older now and they're doing good. And you know, it keeps me going. Like, okay, [my daughter] can do that too. And it gives me something to look forward to... It gives you hope when you see someone else's baby having a first birthday or a second birthday. It kind of...it's like, oh, we can do that too. I look forward, hopefully, doing that with [my daughter]. Or all the surgeries that [other parents children] go through, and you know, just seeing how these little kids, they're so little, but yet they just fight. It's like [these other kids] just never give up. (daughter has heart condition)

For many parents, other family members were also mentioned as essential supportive networks. Family relationships not only provided critical social support, but also helped with coordinating a child's care and providing a sounding board where parents could emotionally vent. Most parents expressed being inspired by the continuous empathy and encouragement shown by their other family members. One mother, in particular, recounted how her mother-in-law was helpful:

My mother-in-law has been that reminder of making me feel like and not just feel but really believe, "yes, [caring for my son] is like an awesome mission"... [She says things] like "your son is, he is, you don't know how many souls he's saving, or things like reflecting about Christ like he has had so many wounds and that's not typical of three year olds. And you don't want it to be, but it is another thing that's like Christ."... I'm always like inspired after I talk to [her]... And I can't hear it enough. You'd think that okay I heard this so many times but it's like

“wow, yeah I got it now.” And [she is] so good at bringing it back, bringing it back. She is constantly saying positive things to give me encouragement and hope. (son has cerebral palsy)

As this mother described, parents frequently needed these hopeful reminders from others, given the rigors of their child’s treatment coupled with other life demands. For parents who were married, the spouse was often mentioned as an important family support person. For instance, one mother commented on the encouragement that her husband provided when she was hopeless:

When you decide to go on Google and look up stuff about statistics, you know, statistically it’s a hard cancer to beat. Looking at some of those percentages of survival that are low. It’s like (sigh) you don’t want to think about it. So, then my husband just tells me, “he’s not a statistic. He, he could do better. You know, everything’s different person to person.” (son has cancer)

During instances such as this, the spouse was able to recognize when the other parent was struggling, and provided positivity during moments of questioning and doubt.

Finally, many parents, particularly those whose children were hospitalized, mentioned medical providers as key individuals who instilled hope. Medical providers offered hope through positive words of encouragement, as depicted by one mother’s account:

His radiation oncologist is really an awesome person. She is willing to do whatever it takes to keep him here. The other day she said, “we are going to kick this cancer’s butt and this isn’t even close to being the end for him. We’re going to keep trying to fight it.” (son has cancer)

Encouraging messages included comfort, compassion, confidence, and reassurance.

Further, parents appreciated when providers drew parallels to other families whose children they had successfully treated. Parents regarded these hopeful comments as holding significant weight because the medical professional was the expert. Many parents traveled across the United States to seek out experts’ opinions and enroll in specialized

treatment programs. For example, one mother, whose son was diagnosed with severe aplastic anemia, described the hope she was able to maintain because of the national credibility and higher success rates from her son's physician:

It's a big scary "if"... It's just [this doctor] is just so good at what he does. You know, it might be an eighty percent survival rate somewhere else, but it's probably a 94-95% survival rate here... This center is an aberration in the world. It's kind of the only place where kids really do survive this and do well. No place else.

In cases like this, parents entrusted medical experts to have the knowledge base and skills to care for their child and hoped that they would be able to cure their child as they had done with other children.

Other members of a child's health care team provided hope to parents by caring for the entire family. For example, one mother described how her social worker saved her life while her son was hospitalized for a brain tumor:

I had no idea [the social worker] would be my best advocate... She gave my kids gas cards, my children lunch tickets — go down to the cafeteria and get whatever you want. You know, my kids have memories of things like Christmas gifts would be donated and she would know that my children wanted this specific thing, or she just had a personal interest in us and gave us that support. She let me cry in her arms. She would hug me and hold me. She had a picture that [my son] drew for her on her door for twelve years. She just saved my life in a million ways that I never would have thought.

Support, like the social worker provided instilled hope in parents by helping families traverse a child's hospitalization with positivity and normalcy. Further, parents reported that this type of care made them feel respected and a part of their child's care team.

Active participation in their child's care was something that many parents desired because it fostered a sense of control that was otherwise lost. One father shared his own experiences with being a part of his daughter's care team and the hope that the medical providers gave to him and his wife:

[The healthcare team] gives us a lot of hope by just their own experiences. They do a good job of getting us involved... They come in there and when we're talking and stuff like that we're really part of that conversation. And they'll ask us a question, "Oh, how's she doing today?" And [my wife and I] will answer, "not doing good." [The doctors respond,] "Okay, well then we should be changing things." So they're taking our advice and our opinions on this stuff. (daughter has heart condition)

**Relying on religious and spiritual beliefs.** Many of the parents talked extensively about how religious and spiritual beliefs served as a source of hope for them. The few parents who did not have a spiritual faith stated that they put their faith in the competency of their child's primary care physician and healthcare team. However, the majority of parents interviewed did report having a spiritual belief system, with most of those parents self-reporting as Christian. Parents talked about how their Christian faith provided a source of hope that was a "rock" amidst the many challenges that they experienced. For instance, one mother described how her faith helped her maintain hope amidst her two son's chronic conditions:

I don't have the feeling of hopelessness because I have strong faith. I just trust that God sees the bigger picture, because you know, you can sit there and ask why, and why, why, why? And the truth is we can't know, and so um, I don't know how [other parents] do it without faith. I don't know how you have hope. I know a lot of people with kids with special needs; marriages break up because they can't take it. And this isn't as severe, but I think that yeah, my faith is the number one thing that has really gotten me through this. (two children have genetic condition)

For this mother, as well as other parents, faith was more than "an abstract concept...it [was] a real personal understanding and relationship" (mother, two children with mitochondrial disease) that was maintained by prayer and having conversations with God and other people.

Through prayer, parents mentioned gaining a new perspective and comfort by recognizing that their current circumstances were in "God's hands." In fact, many parents

stated that God was the only one who carried them through the hardships and knew the future outcome. To expand on this idea, one mother whose son had a severe case of OCD stated:

A lot of times, as a human, you feel like you need to control everything, and it's all on you to control that. But at the end of the day, you know, thank goodness I'm not in control—God is... God is in control and we are not. God has a plan for [my son] as he is struggling and going through all of this. You know, because God wants us to learn something or grow in a certain way. You know, because maybe he has a job for [my son] to do and He needs this kind of courage or discipline or diligence to get through something like this. God will get us through and whatever's to be is to be. I just have to do the best I can, and you know, try to listen to God and help [my son] the best way we can.

However, surrendering to God's plan was often difficult, and several parents shared their pleas of desperation that they included in their prayers to God. One mother, in particular, described some of her recent prayers:

My conversations with the Lord have been just (choking up) keep [my daughter] with us, just don't take her away. You know, [my husband and I] will deal with all those other issues, but if she can just make it through them. I just want her to stay here. And yet, I feel like God wants me to have, um, the kind of faith that like Abraham and Isaac (i.e., biblical reference)—that I'm willing to give [Him] my oldest. It doesn't mean [God] wants to take her, it doesn't mean I want to lose her, but I love [God] more. And I want the Lord to be, um, I want Him to be glorified through this. It's like, I don't want Him to take her away, but I feel like I'm still holding on to her so much. I feel like He wants me to get to the point of saying, "You can have all of me — everything. Everything! Every bit, every child, every... (Crying) So that's, that's the hard part. (daughter has cancer)

As this mother recounted, parents had a difficult time accepting God's plan. Nonetheless, prayer was described as comforting and life-changing. For instance, one mother recounted the insights that she received from God in prayer:

I do believe in miracles and I'm not going to say that I wouldn't pray for [my son] to have a miracle... We may or may not get the miracle in the conventional sense of the word, but is it not a miracle that we are managing as parents? Is not God answering that second prayer every time we make it through the day? And if I am totally honest about myself, can I really say that it would be more miraculous for [my son] to walk across the room tomorrow than it is for me to overcome my own

weaknesses for yet another day? This is how I know that God is with us, and that He is answering our prayers. (son has genetic condition with comorbid health issues)

For this mother, her relationship with God through prayer allowed her to recognize the little daily miracles in her life, despite the debilitating nature of her son's condition. Other parents used phrases such as "growth through the cross" and "Him giving the strength" to describe how prayer provided them with the ability to maintain a hope-filled perspective.

Prayers from other people also provided parents with hope and support. Parents described how other people in their church communities instilled hope through prayer chains and by offering tangible support to the entire family (e.g., meals). One mother described the prayers and tangible support she received from her church group and friends:

All my friends tell me that they're praying for us, and what not, and the people at church. I've had a group of people, you know, special friends from church, who have been praying before and all through this, and I send them updates. Our whole church has been praying. They've been sending us cards. They send my husband and father meals two to three times a week... And then, when we were at the NIH (i.e. National Institute of Health), the lady who checked us in... the lady was just so honest and so nice, and she got out a little thing of oil from her purse and she kind of anointed my daughter, and then she said, she had us hold hands, and she said the sweetest prayer. And she was like, "dear God, you banished so and so from this, and you will banish this growth from this child, because you're an almighty"... I mean, she was so kind. It was so cool. I had one similar to that, with a friend that used to work for me in a prior job. I mentioned to her in an email that my daughter was ill, and she came back with basically the same kind of prayer in an email. (daughter has cancer)

As this mother and other parents expressed, the positive energy of others' prayers and support as "a very powerful thing." (mother, son has severe aplastic anemia)

Parents not only had other people praying for them, but would also have conversations with others where they would talk about their child's health condition in tandem with their spiritual beliefs. One mother recounted a recent conversation that she

had with her dad about the purpose of parenting, and how this conversation reminded her what was most important:

Something my dad told me was as a parent is it's not my job to get you into Harvard or make sure you have this fantastic job. My only job is to get you into heaven. And so the easiest way for me to deal with [my son] is remembering that 'cause he's the easiest kid I could have. My job is basically done. So while it seems really hard some times (chokes up) thinking oh, he needs to learn to eat a cookie or something like that. I mean it's ridiculous little things like that that can be so challenging. But, when you step back and you say my only job as a parent is to get him into heaven, I've won the lottery of kids. He's going to be, hopefully I'll be riding on his coat tails. When I remember what my dad said and think about it in that context it makes [caregiving] a lot easier. (son has genetic condition with comorbid health issues)

These conversations were memorable, significant, and meaningful to parents, particularly when caregiving challenges would surface and parents started to feel hopeless. Thus, parents found comfort in the affirmation and prayers from others because they reminded them about the tenets of their faith—to find hope in something greater and beyond their current circumstances. Further, prayer was seen as a “powerful force” and their church group and family provided the fellowship and community that assisted with parents’ abilities to maintain hope.

**Reframing towards positivity.** A final element of hope included parents’ talk about positivity and how they strategically reframed their circumstances in a positive light. This act involved more than just positive thoughts, but was also something that influenced how parents communicated with others about their child and his or her treatment. For example, parents described maintaining positivity in the conversations they reported having with others and actively seeking out positive examples from other people living in similar situations. Parents reported communicating this way because they regarded positivity as vital to their children’s and families overall well-being. In fact,

many parents viewed part of their caregiving role as being a “positive emotional barometer” for the entire family. For instance, one mother whose son was hospitalized and awaiting test results for myriad chronic health problems stated:

It is okay for your children to see you cry but not when they're here [at the hospital]. Not when they're fighting a battle themselves and they won't be able to fight it themselves. That's why we're here because we gave birth to them and we're their backbone when they don't have a backbone. And if we fall apart when they're in critical condition they're going to fall apart because they run on our emotions... I'm not saying it's not okay to cry, I just don't feel it's okay to cry in front of your child when they are lying in that hospital bed trying to fight. If they see you losing it, they're going to lose it because they trust you — they put all of their trust in you. (son has genetic condition with comorbid health issues)

One way that parents would reframe current negative circumstances in a positive way was by offering words of encouragement to their child. For example, one mother whose son relapsed from cancer described how she used positive communication as a reframing tool for both her and her son:

So you start with your faith and then you start looking at the people that have been consistent, and you start giving thanks for that. And then I remind [my son] of the things that went right, what the reward's gonna be for getting through the next step. I do a lot of [encouraging him] and these conversations with him also encourage me. (mother, son has cancer)

Thus, reframing towards positivity was often described as an intentional and necessary strategy. Positive conversations altered parents' meanings assigned to the current situation and assisted them with finding glimpses of hope amidst chronic uncertainty and feelings of hopelessness.

Other times, parents reported using comparisons to other people who were worse off than them to try and maintain hope. For instance, one mother described how she tried to encourage her son when he would experience moments of despair at the hospital:

You look and you see all these kids fighting cancer. I said, “Robert, do you realize how lucky we are?” I mean, my child's not dying. We're okay. We're okay! You

look at a mom with a little 2 year old going through chemo. My son's thing is not terminal. I'm not worried about him dying. You know, now that I'm giving him a shot of anti-coagulant. There's people a lot worse off than me and my son. We've got enough food to eat, we've got a nice house. Everyone's got challenges, and in my world when you look at some of these other little kids who have cancer or are terminal or whatever, it's like, I'm doing fine. (son has venus malformations)

Thus, encouraging words and comparisons were two ways that parents reframed the situation in a positive light for themselves, their children, and other family members.

Having a consistent network of supporters that reminded parents to rely on faith/spirituality and give thanks for the opportunities that they have experienced albeit their child's condition was another way that parents described using positive communication. Because many of the parents interviewed resided at the Ronald McDonald House Charities, they mentioned this living situation as advantageous in their positive reframing because it connected them to other families with children who have disabilities and illnesses. Families were able to confide in these other families for positive strength and support. Further, the House provided parents and their children with resources and opportunities (i.e., art therapy, Secret Garden) that facilitated in their abilities to find positivity amidst their child's current hospitalization. Through others' positivity parents mentioned how they were able to redefine their current circumstances and receive a new uplifting perspective that they could then share with their child and other family members.

Another aspect of positive reframing involved selective communication, in which parents would avoid negative talk from other people as a way to remain positive. For instance, one mother did not let her husband talk about the future when he was in despair because his negativity was too emotionally draining for the rest of the family:

He was like, well you know, six months from now she might not be here. He was

just, like, it wasn't what he was feeling or thinking, it was more factual. So after a while, he was just like all Mr. Doom and Gloom. I would just shut him down because I just can't hear it. You know, you get to a point where, "if you're just going to keep digging the hole deeper, okay you just go jump in it by yourself. Yes, it's very scary and so because of that you are hopeless. But, you can't be hopeless in front of a seventeen year old. I mean, they're just starting their life. If you're all doom and gloom, what's she going to be thinking?" (daughter has cancer)

Parents regarded positivity so highly that others' negative thoughts and talk was shut down as a way to maintain hope. Other parents used avoidance of certain topics as a strategy to maintain hope. Avoidant topics included talk about the distant future or a child's bleak prognosis. One mother, in particular, mentioned how she reframed her daughter's current hospitalization in a positive light:

You can only look at right now and tomorrow and know that you're prepared for tomorrow in case you need it. And that's really all you can do, until you see how she reacts to different medications or to their circumstances, or whatever. And then you treat that [problem]. And then you go to the next day and treat whatever happened that day... So, I'm living in the moment. I'm the one who's bringing the income into the family. I'm working in the lobby. I'm living in the moment. (daughter has cancer)

During such instances, talking about anything pertaining to her daughter's distant future or prognosis was too emotionally raw and would incite too much hopelessness.

Therefore, many parents like this mother focused on the day-to-day as a way to positively reframe current negative circumstances.

Parents also reported using humor or sarcasm as a way to positively communicate with other family members. For instance, one mother talked about using sarcasm with her daughter when they were in the hospital for her chemotherapy treatments:

But it's very important for us to say [to her daughter], "Hey, it's okay. What would we be doing anyway? It's raining out. Or, you know, it's obviously sunny, but it's really raining and everyone's miserable, so we are truly in a good place." (laughs) Or okay, "I just really wanted to play monopoly for six hours with you, so let's go get the monopoly game — let's get it out and start playing. Or, I need

to learn chess, will you teach me some chess?" (daughter has cancer)

Humor allowed the time to pass more quickly and made in-hospital treatments more bearable. Parents not only used humor and sarcasm with their child, but also with other family members (e.g., spouse, mother). One mother mentioned how her husband's sarcasm and humor helped her maintain a positive perspective when she became frustrated with caring for her son at home:

A typical conversation would be like me texting him and saying, "I'm so overwhelmed with everything we need to do with Adam. I feel like I don't have any time in the day, and um, we have so many things to teach him." And he'll just text me back and say, "Isn't it going to be fun?" He kind of pokes fun at me. (son has genetic condition with comorbid health issues)

These types of light-hearted comments made by her husband were positively received and reminded her to enjoy the little moments with her son. In general, light-hearted comments were seen as necessary in maintaining a positive perspective during the treatment period.

Another communication strategy that facilitated positive reframing was expressing gratitude, in which parents would count their blessings as a way to focus on the positive gains received since their child's diagnosis. For instance, several parents mentioned that their family became stronger as a result of managing a child's treatment. Parents also talked about siblings being closer from spending so much time together. Finally, many parents expressed being grateful that their child was still living, and others reminded them of this reality when they would experience anticipatory grief. For example, one mother recounted what her husband said to help her reframe their children's condition in a positive light:

I think every day they wake up we have hope for tomorrow. And that's what you have to look at because if you sit and you have to look at all the bridges that are

ahead (chokes up) you cannot live. You just can't because it's too sad. (two children have genetic condition)

Thus, by displaying gratitude for the gift of their children's lives, parents like this mother were able to reframe negative circumstances in a positive light and be sources of encouragement to one another.

Parents' expressions of gratitude included talk about the milestones that their child was achieving, particularly when he or she surpassed original expectations from medical professionals. One father described his own experiences with positively reframing his daughter's rare and severe condition by attending to what she could do. He reported sharing this positivity with his wife and other daughter:

I think that all the milestones that she's ever been able to hit have been great. I mean, it's you know looking for the bright spots of her situation. You know, for a normal kid to ride a bike, no big deal. But for someone who, a lot of Angelman's kids can't even walk — for a child like that it's a bigger deal, so you enjoy it. (daughter has genetic condition)

As this father noted, reframing towards positivity often included finding the silver lining perspective amidst a child's condition. This approach required parents to intentionally attend to the positives over the negatives, as well as use communication to maintain that perspective. A different father talked about his renewed perspective on the value of life after having his son relapse for the third time with leukemia:

[My wife and I] are lucky because we get the opportunity to really live life. I mean I would rather be sitting on the couch watching football, rather than being at a dog fight for my kid's life but this is real life. You're out there on a hospital ward with all these other families and kids and it's the real deal. In a bizarre way we are lucky because this is really living.

Parents not only reported their desire to maintain these positive thoughts for themselves, but they would also intentionally disclose these more positive sentiments with other people (e.g., other family members, friends) when talking about their child and

his or her condition. One mother, in particular, mentioned why she chose to focus on positive language when talking about her son with other people:

Yes, it consumes a lot of our day dealing with his issues, but it, the issues do not define how [my husband and I] feel about being his parents. So, if I were to go around talking to everybody about every irritating thing I had to do to deal with his circumstance today I don't think that would paint a clear picture. And that's why we mostly don't really talk about it... I would rather talk to them about like the really cute face he made or something like that. (son has genetic condition with comorbid health issues)

Similar to the statements shared by this mother, parents regarded the gift of their child's life as even more precious because of his or her chronic condition. As a way to preserve their memories of their child, parents desired to focus on the positives and engage in positive communication with others, so as to not miss out on any opportunities while their child was still living. One mother reiterated this point by stating:

I want to be able to look back on that last moment and say it was just amazing. It wasn't me crying or mourning; it was me being happy and thankful for what I have. I'll lose it after the fact. (laughs) I really will, but now is not the right time to do that. (son has genetic condition with comorbid health issues)

### **Summary and Preview of Next Chapter**

Although many families have children living with chronic conditions, there is not a clear understanding about the way that parents talk about their experiences with uncertainty, hope, and hopelessness while assuming the role as parental caregiver. This chapter provided the results of a grounded theory analysis about parents' accounts of experiencing uncertainty, hope, and hopelessness as their chronically ill child received medical or pharmacological treatment. Across the 35 parents interviewed, *comparing self to others* was the core category that emerged from parents' transcripts and connected the other categories and themes within the model (see Figure 1). *Comparing self to others* was described as a recursive communicative and psychological process that involved

seeking information and assigning meaning to differences. Within parents' comparisons, they communicated that information-seeking and holding conversations with others (e.g., other parents, friends, healthcare providers) provided them with a meaningful understanding of their circumstances as they proceeded to construct their "new normal," and this process further assisted them with navigating the tensions between hope and hopelessness. Thus, an analysis of parents' talk revealed how everyday conversations and interactions (e.g., online information-seeking), as well as larger social meanings, may effect parents' constructions of uncertainty, hope, and hopelessness. The next chapter provides further interpretation of the findings.

## Chapter 5: Discussion

I examined parents' talk about three major concepts (i.e., uncertainty, hope, and hopelessness) that are central factors affecting their adaptations to pediatric chronic conditions (Mussatto, 2006). Thirty-five parents completed in-depth interviews and questionnaires about their experiences with uncertainty, hope, and hopelessness as their chronically ill child received medical or pharmacological treatments. All of the parents within the study had children with chronic conditions that were self-classified by the parent as complex, because of his or her condition being rare or severe. In fact, 19 children were hospitalized for treatments or procedures at the time of the parents' interviews. Parents' responses to the interview questions were analyzed inductively using grounded theory (Charmaz, 2006) and constant comparative methodology (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Strauss & Corbin, 1990). *Comparing self to others*, a communicative and psychological process comprised of seeking information and assigning meaning to differences, was the core category that represented these parents' experiences. This iterative process was described as being characteristic of living in a state of chronic uncertainty and assisted in parents' constructions of hope and the "new normal," while also attending to their feelings of uncertainty and hopelessness.

In this chapter, I interpret the contributions of this study, relative to the current backdrop of literature in communication and other disciplines. The first section includes four major conclusions that synthesize the interview data and focus upon how the findings relate to other pertinent literature. Next, theoretical and practical implications are proposed. I conclude by addressing limitations from the present study, and areas where future research would be prudent.

## Major Conclusions

**The “new normal” metaphor described as a response to living in chronic uncertainty.** The diagnosis of pediatric chronic conditions means that parents and children face an illness trajectory of acute episodes and maintenance periods in which families may experience perpetual uncertainty (Björk, 2008; Darcy, Björk, et al. 2014; Schuster et al., 2011). As stressors and challenges persist, families must adapt to a “new normal” state of daily living (Hutchinson, Willard, Hardy, & Bonner, 2009; Nurmi & Stieber-Roger, 2012). As most parents recounted during the interviews, “everything is uncertain;” however, the degree to which that uncertainty impacted parents’ descriptions of normalcy, hope, and hopelessness fluctuated throughout a child’s treatment period and could be tied to the meanings that parents ascribed to the concepts and their interactions with others that shaped such meanings. For example, life during a child’s hospitalization was described as being particularly taxing for parents, and even for those parents whose children were not hospitalized, normalcy was changed from how life functioned prior to their child’s diagnosis. All parents expressed ongoing uncertainties, to some degree, about administering treatments at home, managing co-morbid health issues, balancing a child’s care or hospitalization with other life demands, and maintaining quality of life. Often, when some certainty was granted, such as doctors proffering an established treatment regimen, new uncertainties appeared about medication side effects or how to communicate with other people about ongoing changes.

As increased hospital visits, administering daily medications, and making continuous adaptations characterized daily life, parents frequently commented on the need to construct the “new normal,” so as to accommodate to their child’s illness and

treatment needs, while simultaneously attend to daily living. This “new normal” was seen as a goal that allowed parents to make changes and strive for an ordinary life. In fact, some semblance of normalcy was a feature desired by all of the parents interviewed. However, the restrictions placed on children’s and families’ lives by pediatric chronic conditions limited the extent to which normalcy can occur in the everyday sense, despite researchers regarding it as being important for parental caregivers and their families (e.g., Björk et al., 2006; Darcy, Björk, et al., 2014; Darcy, Knutsson, Huus, & Enskar, 2014; Knafl, Deatrick, Knafl, Gallo, Grey & Dixon, 2013). Thus, changes in how normalcy functions and parents’ constructions of the “new normal” proffer insights about how parents traverse chronic uncertainty and attend to ideas of normalcy. For example, in the documentary, *The Art of the Possible*, Harter and Hayward (2009) followed five families of children living with cancer and, regardless of a condition’s severity, each family showed how normalcy functioned differently so as to live well in the midst of cancer treatment, remission, or recurrence. Parents in the present study who had children living with a variety of complex chronic conditions described similar experiences and advanced the need for constructing the “new normal” amidst their child’s treatment period because previous expectations and lifestyles were no longer tenable. The “new normal” was created by engaging in a variety of behaviors, such as restructuring day-to-day living, surrendering previous future goals for their children, and creating a “home” for their child in the hospital that now became their primary residence.

When discussing the changes made to daily living many parents used the phrase the “new normal” as a metaphor to depict their current life experiences and the continuous transformation involved with living amidst chronic uncertainty. Metaphors,

such as the “new normal,” are pervasive in daily living (Lakoff & Johnson, 1980; Welch Cline, 2011) and provide an insider’s perspective that explains realities through language and how a collective family identity is formed (Charmaz, 2006; Pawlowski, Thilborger, & Cieloha-Meekens, 2001; Sabourin, 2006; Turner & West, 2006). In the context of health and illness, metaphors shape individuals’ understandings, attitudes, and experiences (Babrow & Mattson, 2011) and provide a blueprint for the situational reality that guides communication and action about how to respond during illness (Welch Cline, 2011). In this case, the “new normal” acknowledged the meaningful and significant difference and change in parents’ lives that was derived from the chronic uncertainties characterizing their role as caregivers and parents. This metaphor also altered how they interacted with other people. For example, parents talked about how interactions with other parents of children living with similar conditions helped them understand what the “new normal” entailed. In addition, parents formed comparisons to other parents of “healthy” children and discussed how their life was different from them. Analysis of metaphors such as the “new normal” allows for individuals to “make public the ineffable” and precisely reveals “the qualitative aspects of life” and its meaning through “the artistic use of language” (Eisner, 1991, p. 227).

**The social construction of parents’ uncertainty, hope, and hopelessness was a product and process of social meanings and everyday talk.** Stress is often situated within larger frameworks beyond the individual (Revenson, 2003) and major life stressors, such as managing a child’s complex chronic condition, “are not experienced in a social vacuum” (Revenson, Abraido-Lanza, Majerovitz, & Jordan, 2005, p. 137). Thus, explaining illness needs to be examined at both content and relational levels (Thompson,

Whaley, & Stone, 2011). The larger system of pediatric chronic conditions (i.e., systems theory; Sabourin, 2006) coupled with social interactions affect meanings of “health,” “illness,” and “disease” that directly influences individuals’ behaviors and reactions to specific health states (Welch Cline, 2011). In this case, parents’ individual experiences with uncertainty, hope, and hopelessness were socially constructed through the informational environment comprised of larger social meanings, everyday conversations, as well as intentional and unintentional interactions with other people (e.g., their child, their child’s physician, other parent) that occurred face-to-face and online. The information exchanged during these interactions influenced parents’ uncertainty, hope, and hopelessness.

The language surrounding a child’s complex chronic condition provided a label for what was “different” about the child, and thus “changed” in parents’ lives, and also situated parents in a larger framework characterized by chronic uncertainty. Further, when parents were first told that their child was diagnosed with Downs Syndrome, other rare genetic conditions, heart problems, or cancer, parents had initial reactions to their physicians’ disclosure because of preeminent social meanings assigned to these conditions, particularly information about severity or rarity, prognosis, genetic components, options for treatment, and the ability to maintain normalcy. For example, one mother with two children living with a life-threatening genetic condition talked about how she wished that her children had cancer instead because “I would have known what we needed to do...because they have already proven treatment... I would know what to expect... What it meant to be on study and what it meant to be off... We may still not have had our happy ending but at least we would have had a chance.” Other parents

discussed being grateful that their child “only had hemophilia” (mother) or a less life-threatening genetic condition because “the outcome may be unknown but at least it is not terminal” (father, daughter with genetic condition). Parents also referenced the larger social meanings assigned to their child’s particular condition. For example, two mothers with children receiving in-patient treatment for mental illness mentioned the additional challenges with managing the social stigma related to eating and obsessive compulsive disorders. Managing stigma presents challenges for both stigmatized persons as well as their caregivers, who must use communication to cope and potentially alter others’ negative labels (Smith, 2011). All of these examples demonstrated how parents compared their situations to others based on personal and larger social meanings about their child’s condition.

As parents traversed the treatment period, the process of *comparing self to others* affected parents’ meanings of uncertainty, hope, and hopelessness. For instance, as parents described their interactions with other parents of children living with similar conditions, sought information online, and talked with medical professionals about treatments and their child’s prognosis, these interactions affected parents’ meanings of uncertainty, hope, and hopelessness. Parents then applied this meaning as they compared themselves to others, which then affected constructions of the “new normal,” as well as their abilities to maintain hope and feel hopeless. For instance, messages from other people that included positive examples of other children responding well to treatment, living independently as an adult, or having a high quality of life were contiguous with parents’ efforts to maintain hope. In contrast, bleak statistics about a child’s prognosis, limited information from medical professionals about an established or effective

treatment plan, or unsupportive behaviors from other people (i.e., other family members being negative about a child's prognosis) coincided with parents' feelings of hopelessness, as other scholars have also noted (Uccelli et al., 2013).

Information is a critical part of the parental caregiving experience (Björk et al., 2005; Kerr et al., 2007; McGrath et al., 2007; Ringnér, Jansson, & Hällgren Graneheim, 2011) and parents' information-seeking and conversations with other people informed their constructions of uncertainty, hope, and hopelessness. Often, parents were obliged to interact with others (i.e., medical professionals, the other parent, the child, other family members), such as during hospitalizations or responding to their child's questions while administering treatments at home. Other times, interactions were less obligatory, but most parents still remained active in coordinating care with other family members or participating in online forums through Facebook or Caring bridge sites. In addition, many parents traveled across the country to seek opinions and treatments from specialized experts whose research and clinical trials instilled parents with more hope amidst a bleak prognosis or rare diagnosis. The credibility and success rates from these experts and institutions had personal and social meanings that affected parents' constructions of uncertainty, hope, and hopelessness. Social and communicative factors, such as information seeking and social support have been identified as influential in shaping parents' perceptions of hope and hopelessness during a child's chronic condition (Barrera et al., 2013; Salmon et. al, 2012; Verhaeghe et al., 2007a, 2007b). Similarly, I found that these factors contributed to how parents talked about uncertainty, hope, and hopelessness across a spectrum of complex pediatric chronic conditions.

***Comparing self to others*** assisted parents with navigating the tensions **between *maintaining hope* and *feeling hopeless***. In extant research, hope and hopelessness are conceptualized as being in direct opposition of one another. Hope has been described as a feeling that is a product of thinking and behaving, and is associated with optimistic personality traits (Groopman, 2004; Snyder, 2000a, 2000b, 2002). In contrast, hopelessness is a belief in the impossibility of making changes and a resultant loss of hope due to chronic exposure from uncontrollable stressors (Abramson et al., 1989; Walker, 2001). There was evidence from parents' conversations that they, too, conceptualized hope and hopelessness differently, in a way that was often in direct opposition to one another. Hopelessness was seen as a reactive emotional feeling, whereas hope was an active choice that parents communicatively and cognitively maintained. With hope and hopelessness being conceptually different, yet simultaneously co-existing, the inherent tensions between the two concepts were made apparent. Whether parents' hope or hopelessness assumed precedence was dependent on several factors (i.e., reframing towards positivity, finding a supportive community, relying on religious and spiritual beliefs, suffering from anticipatory grief, dreading the what-ifs, and experiencing overwhelming obstacles) as well as the larger social process of *comparing self to others*.

More recently, communication scholars have suggested that, in addition to being a cognitive concept, hope is also a discursive act that is constructed and negotiated through interpersonal discourse and dialogue (Barge, 2003; Davis, 2005, 2012; Davis et al., 2013). Dialogue is produced collaboratively through simultaneous disclosing and listening, and meanings from these interactions create new ways of understanding

ourselves, others, and the world (Davis, 2005; Wood, 2004). The parents interviewed described maintaining hope as a process of cycling through dialectical tensions (i.e., opposing forces that people experience in their relationships; Baxter, 2004, 2011) between hope and hopelessness. For example, *comparing self to others* while simultaneously finding a supportive community, relying on religious and spiritual beliefs, and reframing towards positivity reconciled these tensions in a way that allowed parents' hope to supersede hopelessness. As other scholars have also noted, hope may be reconciled in dialogic moments (Cissna & Anderson, 1998; Davis, 2005; Davis et al., 2013) and discursively maintained through interactions with other people where empathy, engagement, human connection, vulnerability, creation of possibilities, and social support occur (Barge, 2003; Davis, 2005). Thus, these different attributes of conversations may provide parents with opportunities to find an alternative position that allows both hope and hopelessness to co-exist, with hope preceding hopelessness. Davis and her colleagues (Davis, 2005, 2012; Davis et al., 2013) have noted that certain communication behaviors (i.e., strengths-based language) may allow for discursive tensions between hope and despair to be constructed in a way that allows hope to surmount hopelessness. As described by the parents, finding a supportive community, relying on religious and spiritual beliefs, and reframing towards positivity may be three additional ways that parents can maintain hope while they simultaneously experience chronic uncertainty and hopelessness.

The chronic uncertainty that characterized parents' lives required them to engage in frequent interactions with a variety of people (i.e., medical professionals, other parents, children, family members, and friends), as well as actively seek out information, to

provide the best care possible for their child. Within this environment, the social process of *comparing self to others* allowed parents to navigate uncertainty and construct the “new normal.” This process also influenced parents’ assessments of hope and hopelessness. For example, the weight that parents assigned to grief and positivity, or experiencing overwhelming obstacles and receiving effective social support, could be connected to whether parents’ hope or hopelessness assumed precedence. As several parents noted, messages from other people that were positive, supportive, or relied on faith beliefs assisted parents’ with maintaining hope despite living in chronic uncertainty and feeling hopeless. Interpreted in the context of published literature, this may be because dialogue inspires people to imagine possibilities and take action toward them (Barge, 2003; Davis, 2005). During these interactions, hope may have been constructed through strategies, such as strengths-based language (Davis, 2005; Davis et al., 2013) that reinforce “our inter-human connectedness by normalizing the need for help, and by reminding each of us that, in our humanness, we can and will survive” (Davis, 2005, p. 317). The impact language and messages have on parents’ hope and hopelessness was apparent as they described how different interactions with others (e.g., receiving a terminal diagnosis, hearing about another child living a meaningful life with the diagnosis, reading a bleak statistic, praying with a prayer group), whether occurring online or face-to-face, were influential in how they formed comparisons that then affected their constructions of the “new normal,” maintenance of hope, and feelings of hopelessness.

Finally, family relationships are made through competing, ongoing, and discursive discourses that are inherent in everyday interactions (Pecchinois & Kelley,

2011). Dialectical tensions occur when individuals make decisions or establish meaning as they merge others' perspectives and maintain their individual perspective (Baxter, 2004, 2011). Parents' descriptions of living in chronic uncertainty required them to negotiate larger questions, including: how to coordinate their child's care with other life responsibilities; how to remain informed about their child's condition and be a part of their child's care team; whether their family focuses on the positives or negatives; and, how daily "normal" life functions. The answers to these questions resulted in how parents constructed their "new normal." Simultaneously, dominant discourses pertaining to what it means to be a parent, societal meanings about "normalcy" and "different," and the increased need to surrender control to their child's illness while desiring to be in more control, were all additional factors impacting parents' constructions of normalcy, hope, and hopelessness. Examining parents' talk about uncertainty, hope, and hopelessness provided voice to the tensions surrounding their child's complex chronic condition. For example, parents' language about normalcy, differences, and change signified the struggles of being both parents and caregivers, and the challenges with balancing the needs of a child's condition and treatment while simultaneously maintaining a "normal" life. *Comparing self to others* emerged as the central social process describing how parents discursively managed these tensions, both individually and with other people (i.e., the other parent, friends, other family members). In the study, parents described reconciling tensions between hope and hopelessness by finding a supportive community, relying on religious and spiritual beliefs, and reframing towards positivity. These communicative behaviors created possibilities for parents as they constructed the "new normal," in a way where they lived well despite chronic uncertainty. In many ways, these

behaviors may explain why some parents were able to come to a place of gratitude where they genuinely valued their “new normal.” As one father stated:

[My daughter’s diagnosis] has been a huge eye opener for my wife and I...It’s kind of made us like just slow down and really appreciate every second we have with the kids... We don’t know how long everyone’s gonna be here. (daughter has heart condition)

Positive and supportive dialogue, such as the conversations that this father reported having with his wife and his daughter’s medical providers, have been found to transcend differences and tensions in a way that is hopeful (Davis, 2005, 2012; Davis et al., 2013).

**Positive communication and support facilitated parents’ construction and maintenance of hope.** When individuals are a part of a reliable supportive community that copes with a shared hardship, such as when two parents communally cope (i.e., shared orientation of the problem and adaptation through joint problem-solving; Afifi, Hutchinson, & Krouse, 2006; Lyons, Mickelson, Sullivan, & Coyne, 1998) with their child’s chronic condition, resiliency is a likely outcome from the exchange of support that may assist with the construction of hope and foster a sense of community (Goldsmith & Albrecht, 2011; Davis et al., 2013; Horton & Wallander, 2001; Norris, Stevens, Pfefferbaum, Wyche, & Pfefferbaum, 2008). This is because supportive communities assist with helping individuals live healthier and happier lives compared to people who remain socially isolated (Sullivan, 2013), and parental support and hope, in particular, are associated with increased psychosocial adjustment to managing pediatric chronic conditions (Horton & Wallander, 2001; Mednick et al., 2007). Further, the features within supportive networks are shown to enhance health by providing: (a) feedback and social control, (b) health information and seeking care, (c) tangible support for health, and (d) coping assistance during stress (Goldsmith & Albrecht, 2011). Similarly, other

scholars have found that a child's provision of care and families' quality of life improves when parents feel supported through spiritual advice (Meert, Thurston, & Briller, 2005) or social contact through shared stories (Meert, Briller, Myers Schim, & Thurston, 2008).

The parents who were interviewed expressed similar needs in having a reliable supportive community, and regarded their networks as being critical supporters during their children's hospitalizations and treatments at home. Many of the parents interviewed sought out these communities online and face-to-face, whereas other parents received immediate access to a supportive community by residing at the Ronald McDonald House Charities. Facebook groups, comprised of other parents who had children living with similar health conditions, were significant resources mentioned by most parents. Other parents, hospitals, and non-profit organizations created these online groups for parents to interact with one another. Parents' involvement in these groups mirrored tenets of a typical support group in which parents described uniting around a similar concern, in this case their child's diagnosis or type of treatment, with the purpose of sharing experiences, thoughts, and feelings (Goldsmith & Albrecht, 2011). In these online communities, parents reported exchanging information about their child's health status, treatment, and achievements or significant milestones (e.g., birthdays). Further, parents reported utilizing others' responses and information to form equitable comparisons as they constructed their "new normal."

Parents' supportive networks were comprised of many different types of people including, other family members, friends, other parents of children living with similar chronic conditions, and medical providers. Parents reported that each of these members had important roles in facilitating their abilities to maintain hope, and they often utilized

the different members within their networks for different types of support. For instance, other parents and medical providers proffered useful information to assist with medical decisions and negotiate complex health care systems, whereas family members and friends provided positive encouragement and tangible aid. Different types of networks have been shown to afford different advantages for seeking information and care (Goldsmith & Albrecht, 2011), yet together the entire network has a vital role in maintaining individuals' positive well-being (Revenson, 2003; Revenson et al., 2005). The supportive conversations recounted by parents as they discussed these different network members provided them with reassurance, validation, and acceptance; offered perspective shifts on cause-effect contingencies; coordinated sharing resources and assistance; and enabled disclosure of thoughts and emotions, which are all regarded as pathways that link supportive conversations and networks to positive health benefits (Albrecht & Adelman, 1987; Goldsmith & Albrecht, 2011).

Although social support can substantially assist parents in maintaining hope as they traverse a child's treatment period (Barrera et al., 2005; Barrera et al., 2013), the mere presence of social support may not always be positively received (Albrecht & Adelman, 1987; Goldsmith & Albrecht, 2011; Goldsmith, 2001, 2004; Thompson et al., 2011). Thus, understanding what type of support is preferred and helpful becomes important (Galarce, Ramanadhan, & Viswanath, 2011). In light of this, I found that positive communication and support was described as being advantageous and facilitated parents' abilities to maintain hope. Positive communication is defined as the relationships and processes that are marked by their abundance and resource-producing capabilities to improve a higher quality of life that contains facilitative talk that is generative, enriching,

and enhancing (Ragins & Dutton, 2007; Pitts & Socha, 2013). This type of communication has been shown to directly change or elevate one's affective state, such as maintaining hope amidst adversity (i.e., Fisher et al., 2013; Green, 2015; Prestin, 2013). Scholars have demonstrated that to fully understand the implications of positivity when coping, it is vital to conceptualize positivity as an interactive process and not merely the patient or caregiver's cognitive thought processes about his or her experiences (Fisher et al., 2013; Wilkinson & Kitzinger, 2000). A valuable contribution from the dissertation is proffering some of the positive support processes that may underlie parents' abilities to maintain hope as they traverse uncertainty and interact with other people and information.

One process that parents mentioned as helpful with maintaining hope was spiritual and/or religious support. Spirituality and/or religious involvement has been identified as a way for patients and caregivers to effectively cope with chronic illness (i.e., Koenig, 2008; Kremer, Ironson, & Porr, 2009), and many individuals often report relying upon spirituality or religiosity after the onset of chronic conditions (Glover-Graf, Marini, Baker, & Buck, 2007). Further, hope is often conceptualized as a spiritual idea because it is about meaning, endurance, and determination that are attributes of many spiritual ideologies (Groopman, 2004). The parents interviewed reported relying on religious and spiritual coping, which has also been associated with parents' abilities to positively reframe negative circumstances (Ciarrocchi, Dy-Liacco, & Deneke, 2008; Green, 2015; Grossoehme, Ragsdale, Wooldridge, Cotton, & Seid, 2009; Richards, Wrubel, Grant, & Folkman, 2003; Szczesniak, Zou, Wetzel, Krause, & Grossoehme, 2015). During the interviews, parents described instances where conversations with other

people that shared similar beliefs, as well as group prayers and tangible aid from congregational members facilitated in their maintenance of hope, and other scholars have also mentioned these as being beneficial for parents with chronically ill children (i.e., Szczesniak et al., 2015).

The majority of parents interviewed self-identified as Christians, which is important to note given that Christian hope (i.e., hope resides in life beyond death) derives from God and is one of the three tenets of the Christian faith (i.e., faith and charity being the other two tenets). Researchers have found that Christian hope may provide patients and family caregivers with meaning as they come to terms with a diagnosis and make ongoing treatment decisions (Moltmann, 2004; Pattison & Lee, 2011). Parents' reliance on their Christian beliefs as a source of hope meant that hope encompassed more than the mere medicalized notions of hope relating to a cure and prolongation of life (Clayton, Butow, Arnold, & Tattersall, 2005; Elliott & Olver, 2002, 2007; Pattison & Lee, 2011), but also included spiritual dimensions that took precedence when parents relied on their beliefs as they faced obstacles or felt hopeless. Further, the parents described their Christian hope as more than a belief that they subscribed to, but was also something that they actively participated in through dialogue with God in prayer, as well as interactions with others who shared similar beliefs. These conversations and communities provided the support and meaning necessary for parents as they wrestled with the tensions between hope and hopelessness, and sought to actively maintain hope.

Another process that facilitated positive communication was actively seeking out supportive examples from parents and children living well amidst complex pediatric

chronic conditions. Stories from these other children and families allowed parents to maintain hope as they formed equitable comparisons to other people and gathered information that was reported as being helpful in constructing their “new normal.” For instance, helpful information included stories from other people that embodied characteristics of quest narratives (Frank, 1995), in which other parents would discuss the benefits gained from their child’s illness or proffer suggestions about alternative ways for living meaningful lives amidst chronic uncertainty (i.e., constructing the new “normal”). The act of seeking out these stories not only appeared to serve instrumental functions, but also may have provided parents with the emotional support necessary for managing uncertainty, as other scholars have similarly concluded (Galarce et al., 2011).

Finally, the type of positive communication that assisted with parents’ reframing was similar to strength-based language (i.e., focusing on positive attributes as a vehicle for positive change to help families manage a child’s chronic condition). Davis et al. (2013) found this type of language to be helpful for family members with children diagnosed with mental illness. This type of talk privileges a child’s capabilities over deficiencies (Davis, 2012; Davis et al., 2013) and is a strategy that may help patients and family caregivers feel better and appraise their situations more realistically (Fisher et al., 2013). In fact, when parents did not engage in this type of thinking and talk with other people, parents described feeling hopeless and experiencing anticipatory grief, which was one of the many negative emotions enumerated by parents. Parents’ use of strengths-based language in their accounts of conversations with others focused on the immediate rather than distant future, and recognized goals that their child was accomplishing or positive things occurring (e.g., family becoming closer due to providing vigilant care for

the child, siblings and parents learning to be more empathetic) despite their child's health condition. By engaging in this type of talk with other people, parents were able to develop alternative pathways to bleak situations (e.g., terminal prognosis), be reminded of supportive resources, and recognize their abilities to overcome hardships. Thus, these conversations appear to provide parents with the agency (i.e., motivation to move forward) and pathways (i.e., ability to find ways to reach goals) that Snyder (2000a, 2000b) posits as the primary tenets of hope theory. Further, others' positive stories were reported as being positively transformative in parents' assessments of their own situations, which coincides with research on narratives that signifies how evoking hopefulness through positive and uplifting stories may motivate and inspire individuals in their own hope-filled pursuits (Prestin, 2013).

### **Theoretical Implications**

Individuals socially construct meaning about health and illness, which in turn influences communication and behaviors (Caughlin et al., 2011; Goldsmith, 2001, 2004; Donovan-Kicken et al., 2012; Nurmi & Stieber-Roger, 2012; Wittenberg-Lyles, Goldsmith, & Shaunfield, 2015). Conducting this research was an opportunity to study how parents talk about uncertainty, hope, and hopelessness, and how this talk informs their social constructions of these concepts while caregiving for chronically ill children receiving treatment. Across research on parental caregivers, uncertainty, hope, and hopelessness have been identified as important themes characterizing the parental caregiver experience (Carlson, 2002; Farran et al., 1995; Mussatto, 2006); however, the potential relationships among these related concepts, and the particular role of communication in that process, have yet to be examined, and thus served as the impetus

for conducting the dissertation.

An assessment of parents' talk about uncertainty, hope and hopelessness illustrated the discursive tensions evident between the hope and hopelessness that parents reported experiencing while living within chronic uncertainty, and how parents actively maintained hope through engaging in certain communicative behaviors (i.e., reframing towards positivity, relying on religious and spiritual beliefs, finding supportive communities). Even in parents' accounts of hope, the presence of hopelessness remained, thus representing the both-and relationship between these concepts. This understanding between the dialectical tensions of hope and hopelessness supports tenets of relational dialectics theory (Baxter, 2004, 2011) and challenges uncertainty management theory (UMT; Brashers, 2001). Within UMT (Brashers, 2001), hope and hopelessness are conceptualized as separate, isolated concepts that independently influence uncertainty and subsequent information behaviors. An individual's desire to gain control and foster hope often leads to information avoidance, whereas hopelessness is typically associated with information-seeking (Brashers, 2007; Parrott et al., 2012; Truitt et al., 2012). However, hope and hopelessness are likely to co-exist for parental caregivers of chronically ill children (e.g., Barrera et al., 2013), as also noted by the parents in this study. Thus, basing information behaviors on whether hope or hopelessness exists is futile when these concepts often co-exist and continue to be socially constructed. The both-and relationship between hope and hopelessness, and how the larger social process of *comparing self to others* may allow parents to negotiate these tensions in a way that maintains hope is a valuable contribution from the grounded theory advanced in this dissertation. Further, Bradac (2001) noted the importance of studying emotions in the

processes associated with uncertainty and communication. The results of this dissertation provide important insights about the emotionally-valence language that parents used to describe the chronic uncertainty that characterized their child's treatment period, and how they talked about their emotions with other people.

The grounded theory also extends other communication and social science theories. For example, the core social process within the model, *comparing self to others*, is similar to tenets of social comparison theory (Festinger, 1954; Helgeson & Gottlieb, 2000), social identity theory (Tajfel & Turner, 1986), and self-categorization theory (Turner, Oakes, Haslam, & McGarty, 1994). All three theories posit that social identities are fundamentally relational and comparative. By looking at how the process of *comparing self to others* (i.e., a process that acknowledges the shift in parents' social group membership from the healthy, "normal" group to an illness community) allowed parents to navigate uncertainty, hope, and hopelessness, the grounded theory advances our understanding of the social comparison process by acknowledging the important role that information-seeking and interactions with others has in this process. From online sources and interactions with others, parents described assigning meaning to differences, a process similar to the three types of comparisons articulated in social comparison theory (i.e., lateral, upward, and downward; Helgeson & Gottlieb, 2000; Wright, Janan Johnson, Bernard, & Averbek, 2011). These comparisons were not just cognitively assigned by parents, but were also something that parents reported discussing with others (i.e., spouse, other parents, medical professionals). How these subsequent interactions with others transpired influenced whether parents' reported hope or hopelessness assuming precedence. For example, finding a supportive community in which equitable

comparisons could be formed assisted in parents' maintaining hope, while experiencing overwhelming obstacles due to having a limited support network was described as inciting feelings of hopelessness. The grounded theory advanced in this study shows how the comparison process is iterative as parents continuously traverse uncertainties related to their chronically ill child's treatment.

As a whole, the model acknowledges a systems-oriented approach to understanding parental caregivers' uncertainty, hope, and hopelessness. In systems theory, changes in any part of the system affect the entire system (Watzlawick, Bavelas, & Jackson, 1967). In the grounded theory, I convey how the diagnosis and treatment of many complex pediatric chronic conditions affects parents in a very meaningful and transformative way (i.e., living in chronic uncertainty), and how outside factors (i.e., hospitalizations, other family members, careers) may affect parents' social constructions of uncertainty, hope, and hopelessness. This coincides with research showing that the management of pediatric chronic conditions is considered to be a "family affair" (Roy, 2006; Rolland, 1987, 1999), with parental caregivers having a significant role in a child's treatment (Goldsmith et al., 2011; Wittenberg-Lyles et al., 2015). By focusing on parents' uncertainty, hope, and hopelessness, the grounded theory considers the role of three critical clinical constructs that characterize the parental caregiver experience (i.e., Dillard & Carson, 2005; Kerr & Haus, 2014), and how these emotions may be socially constructed and discursively managed during a child's treatment period. This is a novel attempt given that few theories in family communication recognize the range of emotions family members may experience and the effects of context, such as chronic illness and ongoing treatment, on emotions like uncertainty, hope, and hopelessness (Fitzpatrick,

2006).

Finally, the grounded theory advances knowledge within the communicated narrative sense-making process (i.e., how people communicate to make sense of their relationships and lives; Koenig Kellas, 2005; Koenig Kellas et al., 2010). The grounded theory explicates the processes and content of parents' uncertainty, hope, and hopelessness based upon their accounts of current and past events that transpired within their chronically ill child's diagnosis and treatment. For example, parents' reports of *constructing the "new normal"* demonstrated how they made sense of living a life characterized by chronic uncertainty. This insight is important because processes and content of family stories reveal patterns of meaning, interaction, behavior, strategies, and themes relevant to family functioning and individual health (Koenig Kellas & Kranstuber Hortsman, 2015). This information is important for improving interventionist efforts to help families cope with difficulties, such as pediatric chronic illness.

### **Practical Implications**

Examining parents' talk about uncertainty, hope, and hopelessness has important practical implications as an increasing number of children are affected by chronic health problems (Boyse et al., 2012; Branstetter et al., 2008; Children and Adolescent Health Measurement Initiative, n.d.) and when tensions, such as those between hopelessness and hope, are ignored by family and health professionals, conflict, failed health messages, and poor health are likely outcomes (Pecchioni & Keeley, 2011). In addition, chronically ill children are dependent upon parents for the provision of quality care (Goldsmith et al., 2011; Wittenberg-Lyles et al., 2015), and parents' responses to uncertainty, hope, and hopelessness are likely to impact children's psychological adjustment to their condition

(Page et al., 2012; Rabineau et al., 2008; Steele et al., 2009). Knowledge gained from analyzing parents' talk may indicate potential avenues for communication to inform the messages within current family-based interventions.

One way the information from this dissertation may be utilized is by developing positive messages that assist parents in maintaining hope. Parents' need for hope, as well as some content to include that facilitates its construction, was made evident by the parents interviewed. For example, by focusing on the potential for a positive future rather than past or present complications, on what parents can do rather than what remains unattainable, on parents' abilities to positively contribute to their child's well-being, and on the human spirit or faith to transcend current problems, these messages may facilitate parents' constructions of hope. After all, "hope, like dialogue, is transcendent... Moments of dialogue lead to moments of hope, and moments of hope move families forward into a future with enhanced health and well-being" (Davis, 2005, p. 334). The parents interviewed indicated that two features of hope-filled messages might include language that positively reframes the current situation and references individuals' religious or spiritual beliefs. These messages may be posted online in Facebook groups or included in association websites (e.g., American Diabetes Association, National Cancer Institute) where parents are actively seeking information and engaging with other parents to learn more about their child's diagnosis and treatment. Further, this knowledge may be used to educate individuals who work at non-profit organizations, such as the Ronald McDonald House Charities, about effective ways to support families with chronically ill children. These places are unique environments where parents may receive crucial instrumental and emotional support from both the organization and others who have

shared experiences (Nabors et al., 2013).

Incorporating these messages into organizations and websites where parents interact is important due to the growing reliance in caregivers' active participation in the treatment choices, monitoring, and care of patients, which has transformed the paternalistic model of patient-provider interaction to a shared decision-making paradigm (Institute of Medicine, 2001). This transition has been accompanied by a rapid increase and saturation of health information about chronic illnesses and treatments (Galarce et al., 2011; Viswanath, 2005). In light of these two changes, it is important that parental caregivers have sufficient information and resources, as they are ultimately responsible for the care their child receives and being the "bearer of hope" for the family (Goldsmith et al., 2011; Wittenberg-Lyles et al., 2015; Verhaeghe et al., 2005). Integrating positive hope-filled messages on social networking and informational websites may incite hope for parents. In fact, hope-filled media messages have shown to be effective in maintaining individuals' hope, with positive effects persisting for several days after viewing the media (Frederickson et al., 2008; Prestin, 2013). The need for using these messages to instill parents' hope is important because hope is a primary predictor of social, physical, and psychological well-being for both parents and their children (Frederickson, Coffey, Pek, Cohn, & Finkel, 2008; Lyubomirsky, Diener, & King, 2005; Pressman & Cohen, 2005; Waugh & Fredrickson, 2006).

Finally, because parents are recognized as critical members of their child's care team (Wittenberg-Lyles et al., 2015), health professionals are in a unique position to better understand, assess, identify, and support those parents who are finding it harder to navigate the uncertainty and maintain hope. Medical professionals' understanding of

parents' oscillation between maintaining hope and feeling hopeless, and how messages may be used to form comparisons that construct hope and normalcy, is essential in preparing physicians and other medical professionals in caring for the growing number of families affected by pediatric chronic conditions (Carlson, 2002; Montenegro, Birnie, Graham Fisher, Dahl, Binkley, & Schiffman, 2014).

### **Limitations**

There are several limitations to consider regarding the design and procedures of the study. One limitation is that parents were interviewed once, so the responses reflect a single point of parents' self-reported accounts specific to uncertainty, hope, and hopelessness. Regardless of this limitation, parents had a wealth of current and past experiences to draw upon because of the inclusion criteria requiring their child to be diagnosed for a minimum of six months. In fact, a significant strength of this study was that the interviews allowed for analysis of parents' retrospective experiences as well as prospective expectations for the future. In addition, all of the parents had children who were actively receiving ongoing medical or pharmacological treatment, and 19 children were hospitalized for medical procedures or in-patient treatments at the time of the parent's interview. Nonetheless, in future research, scholars should consider interviewing parents several times over the course of their child's treatment period to longitudinally examine parents' experiences. Finally, because the bulk of the interviews focused on uncertainty, hope, and hopelessness, future researchers may want to broaden the scope of interview topics to assess other salient issues relevant to the parental caregiver experience (e.g., locus of control, self-efficacy, advocacy).

A second limitation stemmed from the fact that many of the parents who

participated in the interviews were fairly homogenous. All of the parents had children diagnosed with complex chronic conditions that were considered by the parent to be rare or severe, and the majority of these conditions pertained to physical health issues. In addition, all parents self-reported as White/Caucasian and the majority of the parents were married Christian mothers. Further, a little over half of the parents resided at the Ronald McDonald House Charities at the time of the interview. Because parents resided at this non-profit organization that provided services for parents with hospitalized children, it is likely that their responses and current living experiences influenced their accounts of uncertainty, hope, and hopelessness. Therefore, the model depicted here needs to be read as a framework that organizes the experiences of this set of parents rather than a more general classification of the experiences for all parents (i.e., single mothers, single fathers), parents without access to these social services, or parents with children who have more common chronic conditions (i.e., asthma) that are less severe. Despite these limitations, many pediatric chronic conditions result in increased hospitalizations and moments of high-intensity acute care from severe episodes of the health condition (Schuster et al., 2011). In the current study, I interviewed parents with children across a spectrum of complex chronic conditions, including some of the more common pediatric conditions (e.g., asthma, cystic fibrosis, diabetes, mental illness; Torpy, 2010). However, the severity of a child's condition was currently heightened because of his or her current hospitalization for high-intensity acute care needs and ongoing medical treatments.

### **Directions for Future Research**

There are several processes and concepts within the grounded theory that warrant

the need for future research. One direction for future research is the examination of different types of parental caregivers across a spectrum of pediatric chronic conditions, including both physical and mental health issues. Because pediatric chronic illness is a “family affair” (Roy, 2006; Rolland, 1987, 1999), other types of family relationships need to be studied to fully develop family-based interventions that attend to the needs of all members. For example, researchers may compare differences between mothers and fathers parenting the same child with the chronic condition. One underdeveloped, yet significant family member’s perspective to consider is siblings of children diagnosed with chronic conditions (Wilkins & Woodgate, 2005; Knecht, Hellmers, & Metzger, 2015). Siblings are often disregarded or neglected by the parent(s) as the focus remains on their sick child (Murray, 2000); however, these other children have a significant role in providing care to the sick child (Knecht et al., 2015). The parents who were interviewed echoed similar sentiments about the important role of that these other children had and the particular challenges that they may experience because of their siblings’ conditions. By interviewing siblings directly, researchers may receive another person’s account of what transpires within families when a child is living with a chronic condition.

Another valuable contribution to future research would be identifying helpful and unhelpful support across a child’s treatment trajectory. Within the categories of problem-solving or emotion-focused support, there are more and less effective support attempts (Goldsmith & Albrecht, 2011). Emotional support messages that acknowledge, elaborate, and legitimate the feelings of a distressed other tend to be perceived as more supportive than those that do not contain these features (Burleson & Goldsmith, 1998; Goldsmith &

Albrecht, 2011; Jones & Wirtz, 2006). The act of giving advice is found to be more helpful when the content, form, and sequence attend to a recipient's face wants (i.e., desires for acceptance and autonomy; Goldsmith, 2004). Thus, considering the nuances and complex nature of "helpful" social support may continue to advance knowledge about how to best meet parents' support needs as they incur stresses and uncertainties while caregiving for chronically ill children. Further, it appears that there may be specific "rules" surrounding what type of communication is considered helpful and when this communication is preferred, so exploring the rules surrounding supportive communication is another avenue for future research.

Second, contrapuntal analysis (Baxter, 2011) would be a useful approach for further examining the dialectical tensions evident in parents' talk about uncertainty, hope, and hopelessness (i.e., parents' conceptions of normalcy). A more thorough investigation of these tensions would also illuminate the dominant discourses influencing parents' talk. For example, further analyses may explore the "chain of discourse" in which "discursive history" (i.e., contextualized current talk in the framework of past talk), "broader cultural discourse" (i.e., societal perceptions influencing sense-making), and "anticipated response talk" (i.e., others' perceptions of the appropriateness of talk) all explain parents' meanings of uncertainty, hope, and hopelessness, as well as other salient concepts related to the parental caregiver experience (i.e., Baxter & Braithwaite, 2008, p. 360). Already, the struggle with being both a caregiver and parent were made evident by parents' accounts, and may provide areas for further exploration.

Finally, given the salience of parents seeking online information and participating in social network groups (i.e., Facebook pages) that then informed their social

comparisons, examining the content within these sources and what is communicated to parents who utilize these sites needs to be studied. Despite the proliferation of these websites and groups, the vast majority of studies utilizing concepts from social comparison theory have investigated face-to-face support groups and the behaviors of patients (Wright et al., 2011). The potential utility for examining computer-mediated support groups, as well as blended groups (i.e., people who others interact with both face-to-face and online), and parental caregivers' interactions with different people on these sites is another avenue for future research.

## **Conclusion**

Within the context of family, health plays a central role in family functioning. Families and health are intertwined in meaningful ways and communication is central to these processes and outcomes (Pecchioni & Keeley, 2011). Theories, such as the grounded theory advanced in this dissertation, focus on how parents communicate about health—a context “where the majority of sense-making occurs for patients and their primary caregivers” (Pecchioni & Keeley, 2011, p. 372)—and assist in understanding the meanings and constructions of parents' uncertainty, hope, and hopelessness while caring for their chronically ill children. In the present study, 35 parents of children receiving treatment for various complex chronic conditions were interviewed about their experiences with uncertainty, hope, and hopelessness. Focusing on these concepts was important due to their significance in affecting parents' adaptation and coping to pediatric chronic conditions (e.g., Herth, 1993; Mussatto, 2006), as well as the importance of parents being the “bearer of hope” for their family (Verhaeghe et al., 2005). The findings were supported by the existing literature, but the descriptions of parents' uncertainty,

hope, and hopelessness, and the core social process of *comparing self to others* that facilitates parents' constructions of these concepts, are unique and provide substantial insight to previous research. Thus, this dissertation proffers both a foundation for future research as well as a guide for practitioners to provide holistic and comprehensive healthcare for myriad families affected by pediatric chronic conditions.

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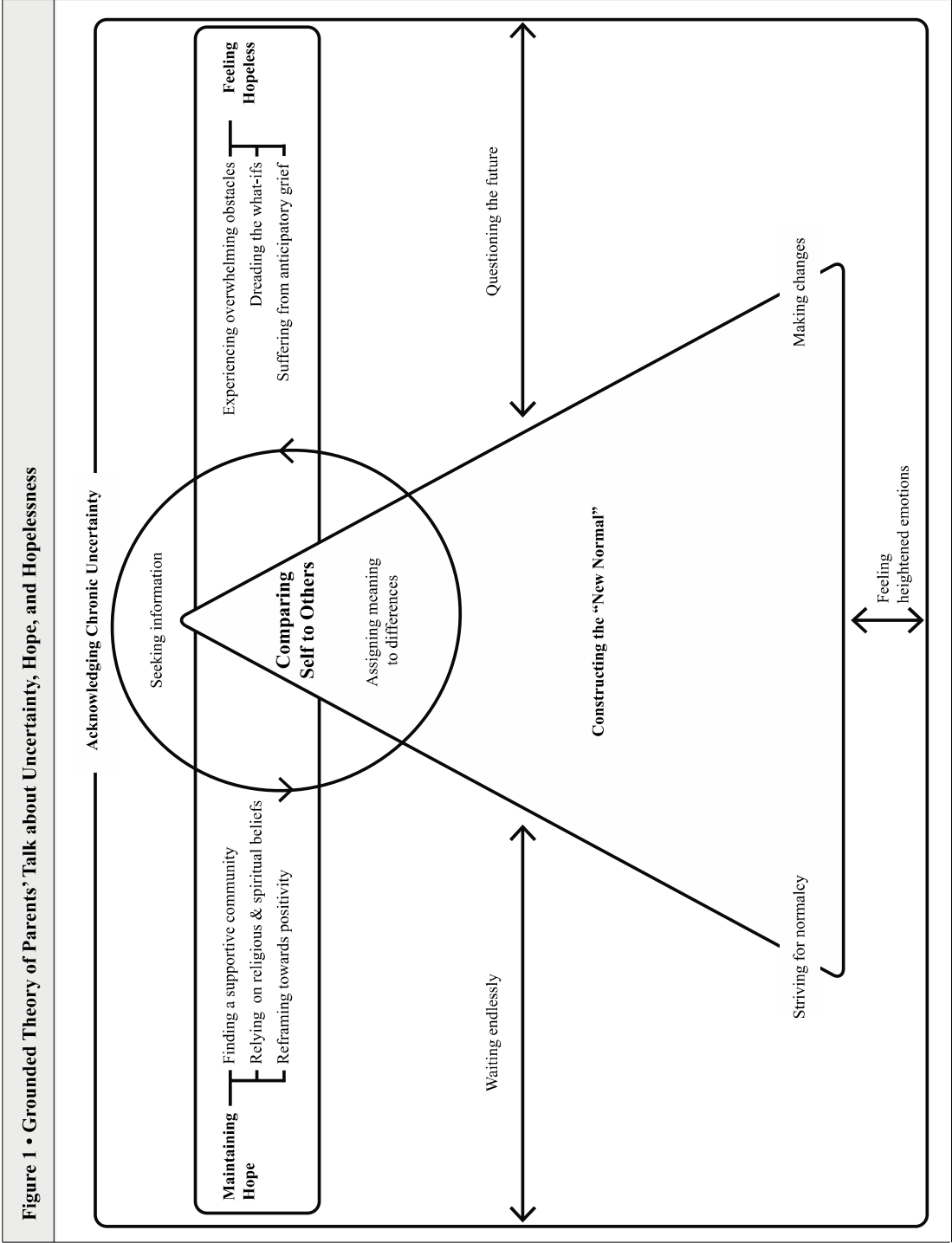
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**Table 1 • Family Demographics of Participants**

Parents	N or Mean	% or SD	Children	N or Mean	% or SD
<b>Sex</b>			<b>Sex</b>		
Female	28	80	Female	12	36
Male	7	20	Male	21	64
<b>Age</b>			<b>Age</b>		
Mean	41.0	9.82	Mean	8.6	6.44
Range	25 - 57		Range	3 months to 17 years	
<b>Place of recruitment</b>			<b>Primary diagnosis</b>		
Ronald McDonald House Charities	20	57	Genetic Condition	12	37
Community	15	43	Cancer	7	21
<b>Type of interview</b>			Heart Conditions	3	9
Both parents	6 dyads	34	Mental Illness	3	9
Only one parent	23	66	Epilepsy	2	6
<b>Total number of children</b>			Cerebral palsy	2	6
1	6	18	Congenital hyperinsulinism	1	3
2	11	31	Type I diabetes	1	3
3 - 4	10	29	Severe aplastic anemia	1	3
4 - 6	4	11	Venus Malformations	1	3
7+	4	11	<b>Number of children with comorbid chronic health issues</b>		
<b>Total number of children living with chronic health conditions</b>			Yes	10	30
1 child - 30		86	No	23	70
2 children - 5		14	<b>Number of years child has been living with diagnosis</b>		
<b>Other caregiving responsibilities</b>			Less than 1 year	6	18
Yes	8	23	2 - 4	14	43
No	27	77	5 - 9	5	15
<b>Mothers' demographics</b>			10 - 14	4	12
Relationship Status			15+	4	12
Married	24	86	<b>Children receiving in-hospital treatment at time of interview</b>		
Single	1	4	Yes	19	58
Divorced	3	10	No	14	42
Ethnicity			<b>Current prognosis (as reported by parent)</b>		
White/Caucasian	28	100	Unknown	11	33
Highest Completed Education			Life-long care	10	31
High School	6	21	Chemotherapy	4	12
Associates	3	11	Terminal	4	12
Bachelors	11	39	Bone marrow transplant	2	6
Masters	6	21	Heart transplant	2	6
Professional	2	8			
Religious/Spiritual Beliefs					
Christian	21	75			
Spiritual	3	11			
Unknown	3	11			
Not religious or spiritual	1	3			
<b>Fathers' demographics</b>					
Relationship Status					
Married	6	86			
Divorced	1	14			
Ethnicity					
White/Caucasian	7	100			
Highest Completed Education					
Associates	3	43			
Bachelors	3	43			
Masters	1	14			
Religious/Spiritual Beliefs					
Christian	5	71			
Not religious or spiritual	2	29			

**Table 2 • Emerging Theory: Theoretical Category, Category, Themes**

Theoretical Category	Category	Theme
Comparing self to others • Seeking information • Assigning meaning to differences	Acknowledging chronic uncertainty	• Waiting endlessly • Questioning the future • Feeling heightened emotions
	Constructing the “new normal”	• Making changes • Striving for normalcy
	Maintaining hope	• Finding a supportive community • Relying on religious and spiritual beliefs • Reframing towards positivity
	Feeling hopeless	• Experiencing overwhelming obstacles • Suffering from anticipatory grief • Dreading the what-ifs

## Appendix A: Semi-structured Interview Guide

*Hi. My name is Katherine Rafferty and I will be interviewing you today. As noted in the consent form, I will be audio recording the conversation so that I can review our discussion later. Your information will remain confidential. You can skip any question that you don't want to answer, and you can choose to withdraw from the study at any time. Please feel free to stop and ask a question if you need me to clarify anything.*

1. To begin, can you tell me a about your child's diagnosis and what your life has been like since then?

(Probing questions: When did you find out the diagnosis and how? What was going on in your life when your child was diagnosed? How, if at all, have things changed?)

2. Since the diagnosis, what has it been like for you talking about your child's illness within your family and with other people?

(Probing questions: Who do you talk to? What do you talk about? What are some conversations that stick out in your mind?)

3. Now I'm going to ask you about different feelings that you might have experienced since your child's diagnosis.

- a. Tell me about a time that you felt uncertain.

(Probe: If so, how did you talk do people during this time? Can you describe other examples/instances? – Remember to exhaust instances.)

- b. Tell me about a time that you felt hopeful.

(Probe: If so, how did you talk do people during this time? Can you describe other examples/instances? – Remember to exhaust instances.)

- c. Tell me about a time that you felt hopeless.

(Probe: If so, how did you talk do people during this time? Can you describe other examples/instances? – Remember to exhaust instances.)

4. Is anything else you would like to share with me about your child's illness or your experiences in caring for your child?

(Probing questions: Is there anything that you might not have thought about before that occurred to you during this interview? Is there anything else you think I should know to better understand your experiences?)

5. As we wrap up this interview, what advice would you have for other parents going through this experience?
6. Finally, do you have any questions for me?

*Thank you for your time.*

## Appendix B: Questionnaire

Participant Number:

Participant Pseudonym:

*The following questions are to provide me with general information about the people who have participated in the study. I realize that some of these questions are of a sensitive nature. Please be assured that your answers will be kept confidential. You may omit any question that you are not comfortable answering.*

1. What is your age (in years)?
2. What is your ethnic group/race?
3. What is your highest level of completed education?
4. What is your relationship status? (Circle one.)  
 Single          Married          Separated          Divorced          Widowed
5. How many children do you have? Please list the number of children and their ages.
6. Do your children live with you? (Circle one.)  
 Yes                  No
7. In addition to other children, would you considered yourself a primary caregiver for *anyone else*? (Circle one.)  
 Yes                  No  
 If you circled yes, who else are you a caregiver for (e.g., adult parent, grandparent)?
8. What is your child's age who is receiving medical treatments (in years)?
9. What disease or illness has your child been diagnosed with?
10. When was your child diagnosed (month/year)?
11. If you have more than one child, do any of your other children have a chronic condition that requires medical attention or treatments? If so, please indicate that.

**Please answer the questions below about your child diagnosed with the chronic illness to the best of your knowledge.**

12. How many symptom-free days has your child had in the last 2 weeks?
13. How many days of school has your child missed in the last 6 months?
14. How many emergency department visits has your child had in the last 6 months?
15. How many in-patient hospital visits has your child had in the last 6 months?
16. How many other medical appointments has your child had in the last 6 months?
17. What is your child currently in the hospital for (e.g., type of treatment)? If you are not sure, please indicate that.
18. How long has your child been in the hospital for this visit?
19. Is there an expected date when your child will return home? If you are not sure, please indicate that.
20. According to your child's primary physician, what have you been told is your child's prognosis (i.e., likely outcome)? If you are not sure, please indicate that.

**Please answer the questions below if you are staying at the Ronald McDonald House.**

21. How long have you been staying at the Ronald McDonald House (i.e., days/months/years)?
22. Is this your first time staying at the Ronald McDonald House? (Circle one.)

Yes                      No

If you answered no, how many separate visits/stays have you had at the Ronald McDonald House in the last year?

23. Are you staying at the House alone? (Circle one.)

Yes

No

If answered no, who else is staying with you at the Ronald McDonald House?

24. Do you participate in any of the family programs (e.g., art therapy, dog therapy, family dinners, movie nights, Rock the House) offered through the House? If yes, please indicate which programs you participate in.

## Appendix C:

## Volunteers needed for research on parents' experiences during a child's chronic or terminal illness.

### What is the study?

During child illness, parents play a critical role as the primary caregiver, decision-maker, and manager of the family. Therefore, we desire to understand parents' experiences with uncertainty and hope when they have a child with a chronic illness. In particular, we are interested in understanding these experiences during the treatment period of illness, since this stage can be a particularly uncertain time for parents.

### Who is eligible to participate?

Parents (over the age of 18 and English speaking) of a child who has been diagnosed with a chronic illness for a **minimum of 6 months**. Some examples of chronic illness include [but are not limited to]:

HIV/AIDS, Cancer, Diabetes, Spinal cord injury, Epilepsy, Schizophrenia, Hypertension, Depression, Anxiety, Eating Disorders, Congenital Heart Problems, Cerebral Palsy, Cystic Fibrosis, Spina Bifida, Severe Asthma

### How information will be gathered?

Participants in this study will be asked to recall stories from their own lives to answer questions about their caregiving experiences. The study will take approximately 1 hour. Participants will be compensated \$25 for their time.

### Contact Information

If you are interested in participating or know someone who may be interested please contact us: **beckerkivolowitz@gmail.com**

IRB#: 14.400



## Katherine A. (Becker) Rafferty

### Curriculum Vitae

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#### Education

- 2015      Doctor of Philosophy, University of Wisconsin-Milwaukee, Department of Communication, **Distinguished Dissertation Fellow**  
 Advisor: C. Erik Timmerman, Ph.D.  
 Dissertation: *“Everything remains uncertain”: Theorizing parents’ communication about uncertainty, hope, and hopelessness while managing complex pediatric chronic conditions*  
 GPA: 3.96/4.00
- 2009      Master of Arts, University of Illinois at Urbana-Champaign, Department of Communication  
 Advisor: Travis Dixon, Ph.D.  
 Comprehensive Exam: High Pass/Pass  
 GPA: 4.00/4.00
- 2007      Bachelor of Arts, University of Illinois at Urbana-Champaign, Department of Speech Communication, *cum laude* with **High Departmental Distinction**.  
 Advisor: Leanne Knobloch, Ph.D.  
 Honors Thesis: *Relationship talk themes: What are we talking about?*  
 GPA: 3.82/4.00

#### Academic Appointments (Teaching)

- 2015-present      Lecturer, Communication Studies Program, Iowa State University
- 2011-2014      Graduate Teaching Assistant, Department of Communication, University of Wisconsin-Milwaukee  
*Communication 381: Introduction to Health Communication*  
*Communication 101: Introduction to Interpersonal Communication*
- 2007-2009      Graduate Teaching Assistant, Department of Communication, University of Illinois at Urbana-Champaign  
*Communication 321: Persuasive Speaking*  
*Communication 101: Effective Principles of Public Speaking*

### **Academic Appointments (Research)**

- 2012-2015      Research Assistant, Patient Advocacy and Research Lab  
Supervised by Katie Mosack, Ph.D., Associate Professor of Psychology,  
University of Wisconsin-Milwaukee
- Participated in University-funded project that examined HIV-related social support, relational functioning, and HIV-related problems among seroconcordant African American dyads
  - Assisted with qualitative and quantitative coding and data analysis that culminated into written manuscripts
  - Managed a team of undergraduate research assistants
- 2014              Research Assistant, Scientific and Medical Communications Lab  
Supervised by S. Scott Graham, Ph.D., Assistant Professor of English,  
University of Wisconsin-Milwaukee
- Provided technical assistance with writing and submitting a *National Science Foundation Standard Research Grant*

### **Professional Work Experience**

- 2012              Centers for Disease Control and Prevention (CDC), McKing Consulting  
*Research Consultant*
- Managed and provided technical assistance in the analysis and writing of qualitative and quantitative research being conducted by CDC and CDC partners
- 2009-2011      Centers for Disease Control and Prevention (CDC), McKing Consulting  
*Health Communication Specialist*
- Coordinated daily communication surveillance reports that analyzed the current communication environment; identified gaps in knowledge from audiences; monitored channel use and coverage in traditional and social media for national and international crises that required a Federal Emergency Response (e.g., 2009 H1N1 pandemic, 2010 Haiti Earthquake, 2011 Japan Earthquake and Tsunami)
  - Examined outcomes and impacts of emergency communication messaging through research and evaluation projects
  - Reported research results and evaluation activities to appropriate stakeholders via formal and informal presentations

### **Publications**

Mosack, K.E., **Rafferty, K.A.**, Billig, A.K., Wendorf, A.R., Brouwer, A.M., & Stevens, P. (in press). An examination of actor-partner social support effects on HIV-related problems and interpersonal outcomes among a sample of HIV-positive African American dyads. *Cultural Diversity and Ethnic Minority Psychology*.

**Rafferty, K.A.**, Billig, A. & Mosack, K.E. (first published online, October 24, 2014). Spirituality, religion, and health: The role of communication and appraisals in the coping process for individuals living with chronic illness. *Journal of Religion and Health*. doi: 10.1007/s10943-014-9965-5

**Rafferty, K.A.**, Cramer, E., & Priddis, D. (first published online, September 18, 2014). Problematic integration and dying wishes: Examining spousal information-seeking about end-of-life care preferences. *American Journal of Hospice and Palliative Medicine*. doi: 10.1177/1049909114550675

**Rafferty, K.A.**, Cramer, E., Priddis, D., & Allen, M. (2015). Talking about end-of-life preferences in marriage: Applying the theory of motivated information management. *Health Communication*, 30(4), 409-418. doi: 10.1080/10410236.2014.889555

**Becker, K.A.** & Freburg, K. (2014). Medical student storytelling on an institutional blog: A case study analysis. *Medical Teacher*, 36(5), 415-421. doi: 10.3109/0142159X.2014.891007

Bradford, L., & **Becker, K.A.** (2012). The role of embarrassment on college student health care seeking decisions. Proceedings from the 2012 American Academy on Communication in Healthcare Research and Teaching Forum. *Medical Encounter*, 26(3), 23.

### **Research Under Review**

**Rafferty, K.A.**, & Sahlstein Parcell, E. (2015). *Family tensions during child illness: An application of relational dialectics theory to group art therapy sessions*. Manuscript submitted for review.

### **Research In Progress**

**Rafferty, K. A.**, & Sullivan, S. L. (2015). "You know the medicine, I know my kid": Taking on the parent advocate role while managing a child's chronic health condition. Manuscript currently in preparation.

Parcell, E., Timmerman, L., **Rafferty, K. A.**, Zmyslinski, A. N., Baker, B. M. A., Stoll, A., Fisher, V., Kohler, K., & Kivolowitz, P. K. *Discourses of deployment: A military child perspective*. Manuscript currently in preparation.

### Conference Presentations

- Rafferty, K. A., & Sullivan, S. L.** (2015). *"You know the medicine, I know my kid": Taking on the parent advocate role while managing a child's chronic health condition*. Paper presented at the DC-area Health Communication Conference (DCHC), Fairfax, VA.
- Rafferty, K.A., & Sahlstein Parcell E.** (2014, November). *Family tensions during child illness: An application of relational dialectics theory to group art therapy sessions*. Paper to be presented at the National Communication Association, Chicago, IL.
- Rafferty, K.A., Billig A., & Mosack, K.E.** (2014, November). *Spirituality, religion, and health: The role of communication, appraisals, and coping for individuals living with chronic illness*. Paper to be presented at the Religious Communication Association pre-conference at the National Communication Association, Chicago, IL.
- Dillon, K.P., Collier, J., Moore, J., Magee, S., Gamreklide, E., **Rafferty, K.A., & Pitts, E.** (2014, November). *Grieving amid the presence of our past(s): How communication technologies are transforming and sometimes challenging the grieving process*. Paper panel to be presented at the National Communication Association, Chicago, IL.
- Mosack, K.E. **Rafferty, K.A.,** Billig, A.K., Wendorf, A.R., Brouwer, A.M., Thomas, C., & Stevens, P. (2014, November). *HIV in a relational context: Understanding social support among HIV-infected African American dyads*. Paper to be presented at the American Public Health Association Annual Meeting, New Orleans, LA.
- Billig, A., Wandrey, R., Wendorf, A., Brouwer, A., **Becker, K.A., & Mosack, K.E.** (2014, May). *The relationship between stress, drinking, and depression within seroconcordant dyads*. Poster presented at the Association for Psychological Science Annual Conference, San Francisco, CA.
- Billig, A.K., Lewis, C., Wendorf, A., Brouwer, A., Wandrey, W., **Becker, K.A.,** Safavi, M., & Mosack, K.E. (2014, May). *Stress, social support, and the actor-partner interdependence model*. Poster presented at the Midwestern Psychological Association Annual Conference, Chicago, IL.
- Becker, K.A.,** Cramer, E., & Priddis, D. (2014, April). *Problematic integration and dying wishes: Examining spousal information-seeking about end-of-life care preferences*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Baus, R., **Becker, K.A.,** Jones, C., & Ksobiech, K. (2014, April). *Making connections and collaborations in the health communication curriculum*. Short course presented at the Central States Communication Association, Minneapolis, MN.
- Kim, S. Allen, M., Ahn, S., Cole, A., Cramer, E.M., **Becker, K.A.,** Choi, C.S., Dilbeck, K.E., Gross, C.M., Hawkins, J.L.M., Jayroe, T.J., Kim, M., Mullane, R.R., Priddis, D.M., Smith, K., Victor, A.K., Willes, K.L., & Zmyslinski-Seelig, A.N. (2013, November). *Testing the evidence effect of Additive Cues Model (ACM)*. Paper presented at the National Communication Association, Washington, DC.

- Becker, K.A.,** Cramer, E., & Priddis, D. (2013, September). *In sickness and in health: Seeking information about spousal end-of-life preferences*. Poster presented at the International Conference on Communication in Healthcare, Montreal, Quebec.
- Billig, A.B., Brouwer, A., Wendorf, A.R., Thomas, C., Olinger, R., Wandrey, R., **Becker, K.A.,** & Mosack, K.E. (May, 2013). *Social support, perceived stress, depression, and anxiety among HIV-positive dyads*. Poster presented at the Midwestern Psychological Association, Chicago, IL.
- Becker, K.A.** (2013, April). *Medical school blogs and the expressive writing paradigm*. Paper presented at the Central States Communication Association, Kansas City, KS.
- Becker, K.A.** (2013, April). *Medical student blogs and support solicitation strategies: An examination of Indiana School of Medicine Tour the Life blogging website*. Paper presented at the Central States Communication Association, Kansas City, KS.
- Becker, K.A.,** & Freburg, K. (2013, March). *Presence of shared experiences, virtual stories, and relationship management: An exploratory study among medical student blogs on "Tour the Life"*. Poster presented at the DC-area Health Communication Conference (DHC), Fairfax, VA.
- Peterson, J.L., **Becker, K.A.,** & Bradford, L. (2012, November). *"I'm too embarrassed": College students' reasons for delaying and avoiding health care*. Paper presented at the National Communication Association, Orlando, FL.
- Bradford, L., Peterson, J.L., **Becker, K.A.** (2012, October). *The role of embarrassment on college student health care seeking decisions*. Paper presented at the American Academy on Communication in Healthcare, Providence, RI.
- Bradford, L., Peterson, J.L., & **Becker, K.A.** (2012, September). *Embarrassment and health care-seeking decisions of college students*. Poster presented at the Medical College of Wisconsin Research Day, Milwaukee, WI.
- Stoll, A., & **Becker, K.A.** (2012, July). *How and why we lie: The use of deception in dating relationships*. Paper presented at the International Association for Relationship Research, Chicago, IL.
- Vidoloff, K.G., **Becker, K.A.,** & Freberg, K. (2012, April). *Analysis of media framing across traditional and social media during the Japan radiation emergency: Implications for emergency risk communication practitioners*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Bradford, L., Peterson, J.L., & **Becker, K.A.** (2012, April). *Embarrassment and college students' health care seeking decisions*. Seminar presented to the Center for Patient Care and Outcomes Research (PCOR), Medical College of Wisconsin, Milwaukee, WI.
- Vanderford, M.L., & **Becker, K.A.** (2009, November). *Exploring stability and change at the intersection of risk and crisis communication: Theoretical and research convergence*. Seminar presented at Health Communication Division pre-conference at the National Communication Association, Chicago, IL.

**Becker, K.A.** (2008, November). *Relationship talk themes: What are we talking about?* Paper presented at the National Communication Association, San Diego, CA.

### **Awards**

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| 2015 | Renee A. Meyers Scholarship, Communication Department, University of Wisconsin-Milwaukee <ul style="list-style-type: none"> <li>▪ Awarded \$2,000 for excellence in teaching, research, and service</li> </ul>  |
| 2014 | Distinguished Dissertation Fellowship, University of Wisconsin-Milwaukee <ul style="list-style-type: none"> <li>▪ Awarded highly competitive, merit-based University-wide fellowship for 2014-2015 academic year</li> </ul>   |
| 2014 | Melvin H. Miller Outstanding Doctoral Research, Communication Department, University of Wisconsin-Milwaukee <ul style="list-style-type: none"> <li>▪ Awarded for excellence in research</li> </ul>  |
| 2012 | First Year Student Success Award, University of Wisconsin-Milwaukee <ul style="list-style-type: none"> <li>▪ Awarded for being the person on campus who has helped first-year students the most in college (nominated by the students)</li> </ul>   |
| 2011 | Chancellor Scholarship, University of Wisconsin-Milwaukee <ul style="list-style-type: none"> <li>▪ Awarded \$6,000 merit-based scholarship</li> </ul>   |
| 2007 | Senior 100 Honorary, University of Illinois at Urbana-Champaign <ul style="list-style-type: none"> <li>▪ Awarded for being one of the top 100 graduating seniors (Based on academic achievement, leadership, and University service)</li> </ul>   |
| 2007 | Outstanding Service Award, University of Illinois at Urbana-Champaign <ul style="list-style-type: none"> <li>▪ Awarded for developing an effective and productive service program for the largest national collegiate Panhellenic community (Nominated by students, faculty, and administration)</li> </ul> |

### **Service**

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|--------------|---|
| 2014-Current | Qualitative Health Research<br><i>Reviewer</i>  |
| 2014         | American Public Health Association Conference<br><i>Reviewer</i>  |
| 2012-2015    | Ronald McDonald House Charities Eastern Wisconsin<br><i>House Volunteer, Reviewer for High School Senior Scholarships</i> |
| 2011         | Midtown Educational Foundation<br><i>Reading Instructor, Mentor</i>   |

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| 2010      | Centers for Disease Control and Prevention, Emergency Communications System Embedment Project, Atlanta, GA<br><i>Research participant</i> |
| 2010      | Helping Hands Medical Mission, Escuintla, Guatemala<br><i>Triage Assistant</i>  |
| 2009      | Upward Bound College Preparatory Summer Institute, University of Illinois at Urbana-Champaign<br><i>Reading Instructor</i>                |
| 2008-2009 | Family and Graduate Housing, University of Illinois at Urbana-Champaign<br><i>Recreation Assistant, Pre-school Assistant</i>              |
| 2005-2006 | Panhellenic Executive Board, University of Illinois at Urbana-Champaign<br><i>Vice President of Service</i>                               |

### **Professional Workshops**

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| 2013 | Completed two Professional Grant Writing Workshops (Facilitator: Kari Wittenberger Keith, Ph.D.), University of Wisconsin-Milwaukee |
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### **Professional Affiliations**

National Communication Association (NCA)  
 American Public Health Association (APHA)  
 Kentucky Conference on Health Communication (KCHC)/DC-area Health Communication Conference (DCHC)  
 Central States Communication Association (CSCA)